



British Polio
Fellowship

thebulletin

The official magazine of The British Polio Fellowship

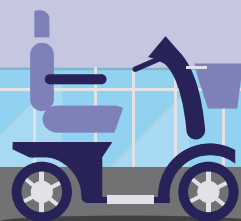
SUMMER 2017



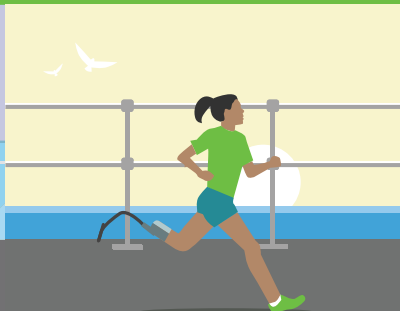
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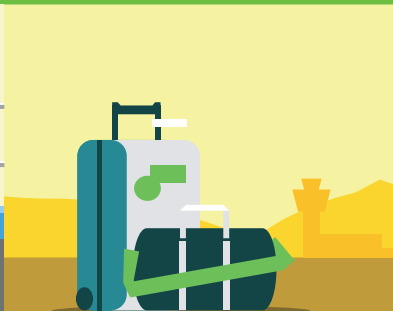
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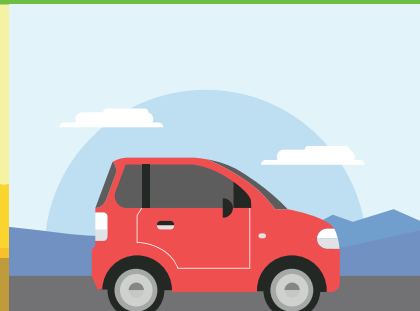
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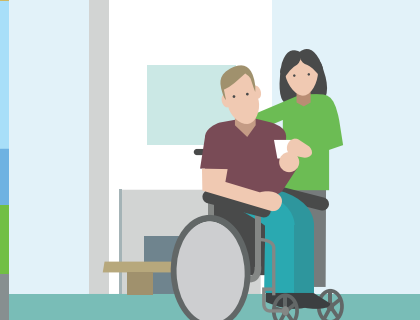
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Cover Story

Ted Hill, Dirk Pilat and Gwenda Cope launch The British Polio Fellowship RCGP e-Learning module at the Indoor Games in Leicester.

Message from the Chief Executive

Welcome to the Summer 2017 issue of **the bulletin**. We have many exciting things to report on, over the coming pages. The year is certainly going by quickly already; the National Indoor Games in Leicester have come and gone, and as I write this we are already well into our National Roadshow tour of the country.

We start with some very exciting news on a new e-Learning initiative we have designed in partnership with the Royal College of General Practitioners (RCGP). Some of you present at this year's Indoor Games may recall the course being announced for the very first time; here in **the bulletin** you can read in full detail what the course is about and how it will help GPs diagnose PPS more effectively and lead to better care pathways for people living with PPS.

As well as that, we have the usual Indoor Games report, complete with many spectacular images that are a fitting memento to another great weekend. Also, we have information on how branches and members can benefit from working with their local Rotary, Freemasons and British Lions groups, how **the bulletin** is changing, and a report from our Trustee, Bosik Gharapetian, about a PPS self-management course he attended at St Thomas' in London.

Royal College of General Practitioners

I'm extremely pleased to announce that in partnership with the Royal College of General Practitioners (RCGP), we have produced an e-Learning course for GPs that is intended to reduce the current unacceptable six year wait on average for PPS diagnosis.

The course will greatly enhance the knowledge of GPs and other primary care providers when it comes to PPS. It should greatly improve the chances of a quick diagnosis for members and those with PPS in general, we hope preparing the way for an end to long delays for people with PPS to obtain the help and support they need. Like our *Post Polio Syndrome: A guide to management for healthcare professionals* information booklet, we're very excited about the new GPs course - and in conjunction with the RCGP - we believe real positive change in the diagnosis and management of PPS is only around the corner. I would like to personally thank everyone at the RCGP for their help, especially Dr Dirk Pilat FRCGP, Medical Director for e-Learning, who has consulted with the charity in recent months and who launched the new course to members at the Indoor Games. To find out more on the course and the RCGP, turn to pages six to nine. Thanks as well to Dr Robin Luff for his efforts.

National Indoor Games 2017

Talking of the Indoor Games, I'm pleased to report that this year's event was the most attended Games ever at the Leicester Marriott Hotel. We say it gets better and better each year, because it does! This year was no exception; a huge congratulations to the North West Region for once again claiming the Top Region prize. This was their second Top Region win in a row, so the stakes are already hotting up for next year's event. As this is the second year in a row that the Games registered a record attendance, it's extremely encouraging to see that the Games continue to get even more popular, remaining as important as ever to members from all corners of England, Scotland, Wales and Northern Ireland. I'm sure you'll agree that the images on pages 10 to 13 certainly do justice to how brilliant this year's Games were.

Roadshow updates

As I write this **bulletin** intro, we have already kick-started our National Roadshow tour of the country to consult with members on what the longer term future holds for our charity and what we can improve upon in the short-term.

In this issue of **the bulletin** we have a few short notes and photos from Leicester, Gloucester, Aldwark (Yorkshire), Edinburgh and Newcastle on page 16. Be sure to keep an eye out for a full analysis and conclusions from the roadshows in a future issue of **the bulletin**.

Rotary; Freemasons; British Lions and other organisations

I'd like to take this opportunity to prompt members and branches of the charity to work with their local Rotary, Freemasons and Lions groups, along with other organisations. Turn to page 20 to read more on this.

PPS self-management programme

In November 2016, one of our Trustees, Bosik Gharapetian, attended the PPS self-management programme at St Thomas' Hospital. Taking place over a two week period, the multi-disciplinary programme was led by an occupational therapist and a physiotherapist. It also included input from a psychologist; a psychiatrist; consultants from the Lane Fox Unit; and a dietician; among others. You can read more about the programme itself, and Bosik's experience and feedback on pages 46 and 47.

bulletin changes

In my last message (**the bulletin** Spring 2017), I ended by confirming that the number of **bulletins** printed each year would be going from six, to five. As I mentioned, this was decided after much consideration, and it was felt that this was the best way to maintain the quality and volume of members' content, to keep a regular **bulletin** coming out to you, and at the same time making considerable savings on print and postage.

We have listened to members' needs on this topic and tried our best to keep everyone happy. We know that is a very difficult balance so if you have strong views on the new paper being used for **the bulletin**, please do let us know either here at Central Office, by emailing info@britishpolio.org.uk or thebulletin@beyondpr.co.uk

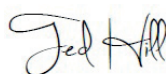
A reminder that an email or website download is the lowest cost way of distributing **the bulletin**, so many thanks to those members who already receive the magazine this way. Please let us know if you would prefer to receive **the bulletin** electronically rather than via hard printed copy in the post.

Richard Flint and Barbara Wood Awards reminder

I would also like to remind members that the deadline for entries for the Richard Flint and Barbara Wood Awards is 23 June. If you haven't yet done so, please get your submissions in now!

Trustees' contact

As an aside, I would like to end by reminding members who wish to contact Trustees that they should do so through me. I am in regular contact with the Trustees, and report to them all correspondence I receive from members. If you would like to contact a Trustee, please contact me on 01923 281 099, or by email at tedhill@britishpolio.org.uk



Ted Hill MBE
CEO

PPS Awareness course for GPs

Many readers of *the bulletin* no doubt have tales of inadequate diagnosis times and support when it comes to PPS. Many members' Polio is not even recorded on medical records and it can be extremely frustrating explaining symptoms to health professionals to find they don't really have the knowledge or understanding to help. This was identified as a major problem for members some time ago, and after much background research and dialogue with various external bodies, we're finally set to see positive change for the diagnosis and management of PPS.

An innovative partnership between the Royal College of General Practitioners (RCGP) and The British Polio Fellowship has led to the development of the new course which is set to reduce the current six year wait on average for a PPS diagnosis in the UK.

Those of you present at the Indoor Games this year may remember Dr Dirk Pilat FRCGP, Medical Director for e-Learning of the RCGP, unveiling the new course with Ted Hill.

The course was promoted from 21- 22 March to GPs at Pulse LIVE, a major national event designed to meet the education and networking needs of grassroots GPs. With many GPs (who are the target audience for the course), attending, Pulse LIVE presented a great opportunity to unveil the course and the resulting feedback from GPs meant the course was thoroughly tested prior to the launch.

Members of The British Polio Fellowship's Expert Panel worked with specialists from the RCGP for several months to create the course; overall, it seeks to address the current low awareness levels of PPS across the primary medical community.

Regular readers of *the bulletin*, and those connected to The British Polio Fellowship know only too well just how low levels of awareness are. Some of you will recall the YouGov research from 2015 that showed 93 per cent of the population are unaware of PPS, whilst in a 2013 survey, 69 per cent of GPs rated their knowledge of PPS as 'low'.

One of The British Polio Fellowship's aims is to help those living with the late effects of Polio and PPS get

their PPS diagnosed faster – whether they are members or not – and helping GPs become more aware of the condition is a win-win for both the NHS, those living with PPS and their families.

"GPs have an essential role to play in the diagnosis and management of chronic neurological conditions such as PPS and in working with us to help develop this course, the RCGP is not just recognising the issue, but taking practical steps that will have a real impact on the many thousands living with PPS in the UK," said Ted Hill.

"The aim of the course is to significantly raise awareness of PPS, with a particular focus on its presentation, recognition and diagnosis," said Dirk Pilat. "The physiology behind the symptoms of PPS is explored, and guidance is given on management strategies, providing the knowledge and tools needed to diagnose PPS and for GPs to refer such cases to a neurologist for further assessment with confidence."

The British Polio Fellowship decided to work together with the RCGP as it works to promote excellence in primary healthcare. The RCGP is the professional membership body and guardian of standards for family doctors in the UK. As a voice for GPs and patients, it speaks up for the standards in primary care, plays a lead role in the formation of policy in key areas such as GP revalidation and takes part in consultations issued by the government and other organisations. The RCGP's focus on GP training and development is a key area that The British Polio Fellowship wants to influence, especially when it comes to quickly and successfully diagnosing PPS – hence this new course.

The RCGP works hard to improve GP education and training so that GPs' overall knowledge is the best it can be. This new course that the RCGP and The British Polio Fellowship have put together will help GPs nationwide understand PPS better – something that The British Polio Fellowship knows must happen given the complexities affecting those living with PPS and how these present in GPs' surgeries.

"PPS is not easy to establish because the diagnosis is one of exclusion," said British Polio Expert Panel and RCGP member, Dr Robin Luff. "Symptoms such as new muscle weakness, cold intolerance and pain can mimic



Royal College of
General Practitioners

Post Polio Syndrome

Acute polio - recovery

The majority of people with polio recover fully. Initial paralysis can remain static for days or weeks before a slow recovery over several months. By three months, 60% of muscle strength recovery in partially denervated muscles has occurred, rising to 80% by six months. Further improvement occurs over the next few years.

Muscle strength recovery occurs by several physiological processes. These include:

- Terminal sprouting. During recovery from polio, brain stem and spinal cord motor neurones can grow new terminal fibres
- Myofibre hypertrophy. The remaining innervated muscle fibres hypertrophy with exercise and activity
- Fibre-type transformation. The change from type II fibres (fast twitch) to type I fibres (slow twitch)
- Ongoing denervation and reinnervation
- Reinnervation of unoccupied neuromuscular junctions.

Bed rest was the mainstay of treatment and medical input usually consisted of surgical interventions. Common operations at the time were achilles tenotomy to correct equinus deformity, nerve grafting, muscle re-alignment, and joint fusion. Electrical stimulation was used for pain, and orthotics were provided. Discharge usually occurred at age 18 and patients were advised to keep active – 'use it or lose it'.



David's experience

I was 22 years old when I contracted Polio in 1965. I remember it vividly. What began as a high fever was followed by the most appalling pain in my shoulders, back and arms. I didn't know what to think in terms of what could be causing the pain.

The next day, I was dragging my leg and my right arm was swinging at my side like a bag of wet sand and dragging me down. I couldn't cut up food, or pour drinks and the pain was intense.



4/23




other diseases, so it is important to rule these out before PPS is ruled in. The British Polio Fellowship course in collaboration with the RCGP provides the pathway necessary for GPs to do this, as early intervention is crucial in the successful management of the condition.”

The newly developed e-Learning module looks at PPS in detail and breaks down the condition into several strands and areas, ensuring GPs can acquire the necessary knowledge of PPS as best as possible. The course looks at the presentation of PPS, how it may be diagnosed and gives advice on management strategies.

After GPs finish the PPS course, they will be able to competently review the basics of acute Polio infection; be aware of the risk factors for developing PPS; understand the difficulties in making the diagnosis of PPS; have some detailed knowledge around the main symptoms of PPS; understand the principles of managing these symptoms and the importance of the multi-disciplinary team; have a list of resources for patients living with illnesses; and understand the pathophysiology and epidemiology of PPS.

Whilst the course cannot be replicated in its entirety here in **the bulletin** due to space, the length of the course itself, and some of the extensive medical terminology used, the example slides in this article give an idea of what GPs will learn and as a result, how they will be able to help those living with PPS. However, we can explain in a bit more detail some of these aspects.

In terms of epidemiology, GPs will learn how the World Health Organisation's (WHO) Global Polio Eradication Initiative has reduced the worldwide incidence of acute Polio by 99 per cent since its launch in 1988. They will also learn that despite this great success, there are 12 – 20 million people worldwide living with the late effects of Polio, according to Post Polio Health International. (Some commentators believe this figure could rise to as many as 40 million worldwide living with PPS, by the time Polio is finally eradicated).

UK surveys show a 60 per cent prevalence of PPS in Polio survivors, and despite there being no new cases of Polio in the UK since 1982, the late effects of Polio and PPS will persist in the population for generations to come. 



Royal College of
General Practitioners

Post Polio Syndrome

Hypotheses for the development of PPS

There are many proposed hypotheses for the development of PPS, but the most widely accepted explanation consists of the components below.

- Degeneration of the terminal axons and motor neurones which remain following recovery from the acute illness. This is caused by excessive metabolic stress being put on remaining motor neurones, as a result of over use.
- The denervation and reinnervation process that begins in the initial recovery of muscle strength diminishes with time.
- At first, collateral sprouting of adjacent motor neurones leads to an increase in motor units. In time these become satiated, reaching a point when further reinnervation is no longer possible. This uncompensated denervation causes muscle atrophy leading to weakness.

Degeneration of terminal axons can also affect the neuromuscular junction leading to abnormal muscle fatigability. Muscle compensation includes replacing fast-twitch muscle fibres with slow-twitch. This results in symptoms of muscle fatigability and pain when patients use a lot of energy.

The energy cost of walking for PPS patients can be as much as 40% higher than in healthy comparisons.



Normal



Acute Polio



Recovery
then Stability



New
deterioration:
PPS



5/23



Royal College of
General Practitioners

Post Polio Syndrome

Epidemiology

Since its launch in 1988, the World Health Organisation's Global Polio Eradication Initiative has reduced the worldwide incidence of acute poliomyelitis by 99%.

While this is great news, there are 12-20 million people worldwide living with the sequelae of polio according to Post-Polio Health International.

Post-polio syndrome (PPS) is a cause of chronic and progressive neurological disability, characterised by a new deterioration in function after a long period of stability; usually in excess of 15 years. The key symptom is muscle fatigue and weakness, but generalised fatigue, pain and respiratory compromise can also occur.

In the UK, there are around 120,000 people living with the effects of polio. UK surveys show a 60% prevalence of PPS in polio survivors. Despite there being no new cases of 'natural' polio in the UK since 1982, the effects of the epidemics of polio during the 1950s will persist in the population for many years to come.




POLIO GLOBAL
ERADICATION
INITIATIVE every fast child



2/23



Examples of the slides.

 Again, this is something that those taking the course will learn. Also included in the course materials are numerous case studies of British Polio members; their stories are told to reinforce the facts and figures being presented, and remind GPs and others that there is a very personal aspect to PPS as well.

The course states that the risk profiling for developing PPS is not clearly understood, though some suggested factors include if Polio was contracted over the age of 15; if there was permanent impairment after initial recovery; if the person is female (although many women in many studies had more severe and widespread Polio); if there was a longer period of time since the acute disease; and if there was a presence of overuse symptoms during the stable period after initial Polio – for example, muscle fatigue, cramps and twitching.

On the course, GPs will also learn that when approached by a patient who presents some of the symptoms of PPS, it helps to ask themselves three questions:

- 1. Has the patient had Polio?**
- 2. Are their symptoms due to a different condition or disease?**
- 3. If the new symptoms are attributable to Polio, are they mechanical or due to a new neurological deterioration?**

Some people may think the first question is an obvious or straightforward one, but GPs are advised to remember that some people don't remember having Polio in their childhood, or their medical records may not be complete. It's important that GPs ask for details of childhood illnesses and any treatments or hospitalisations they may have had, along with any long-standing weaknesses or wasting of muscles.

It's equally as important to remember that even if a patient has a history of Polio, their symptoms may not be attributable to PPS – this is why the second question is asked. For the last question, it's important that GPs distinguish mechanical issues from new neurological weakness. Mechanical weakness can result from early degenerative joint changes in a previously affected limb or in unaffected areas compensating for weakness elsewhere. GPs are encouraged to ensure that patients have adequate information about their condition, and to signpost them to sources of support.

As detailed in the last issue of *the bulletin* (Spring 2017), The British Polio Fellowship's new Parliamentary Ambassador, Rehman Chishti MP informed the House of Commons on 7 February during Health Questions, that low awareness of PPS is leaving patients waiting up to six years for a diagnosis. The Parliamentary Under-Secretary of State, David Mowat, acknowledged that, "awareness of the condition (PPS) is not as high as it could be, and that more needs to be done alongside the work of The British Polio Fellowship on GP education, training and information."

This new course for GPs and The British Polio Fellowship's partnership with the RCGP is putting the Under-Secretary of State's words into practice. It has the potential to transform the lives of those living with PPS, giving them the support they need for an early diagnosis, and facilitating the implementation of an effective PPS care management plan.

We are naturally excited and optimistic about the value of our partnership with RCGPs, and believe this new course could signal a major breakthrough in diagnosis times; we will of course report via these pages as soon as there's any meaningful data or feedback to report.

As always, the charity and *the bulletin* are interested to hear your stories, experiences and views when it comes to PPS diagnosis, and your feedback and comments help to define the targeting of resources and campaigns for future months and years.

Please send in your thoughts, views, stories and experiences on this article and indeed on anything else that's on your mind to do with Polio, PPS, The British Polio Fellowship, benefits, accessibility, etc. It really is your *bulletin* and it's members' views and experience that generally provoke the most interest and engagement from other members. So, many thanks for all your contributions and please keep them coming.

As always, you can either email *the bulletin* Editorial Team at thebulletin@beyondpr.co.uk, speak to Kripen or call Central Office on 0800 043 1935.

To find out more about the RCGP, visit www.rcgp.org.uk 

National Indoor Games 2017



Medal winners with Dr Dirk Pilat FRCGP, Medical Director for e-Learning at the RCGP.

Top row, left to right: Mary Barker and Bill Burton; Dee Cartwright and Karen Pike; Ann and Dennis Kay; and Mary Davison.

Bottom row, left to right: Aidan Linton-Smith; Joe McVeigh; Anna Tizzard; and Alan Weir.

Red rose team just loves annual Leicestershire competition

The North West Region of The British Polio Fellowship successfully defended its position as Top Region of the National Indoor Games, at this year's event on Saturday 18 March.

Led once again by Branch Chairman Mike Griffiths, the North West team overcame strong competition to claim its second consecutive Gordon Lumb trophy. A string of strong individual performances from North West team members ensured North West won this year's 'War of the Roses', finishing just ahead of the typically strong Yorkshire Region, who returned to the top four of the Indoor Games after a year's absence.

Cementing his reputation as the man to beat at Draughts, North West's Andrew Gilliland once again claimed top spot at the chequered board, whilst the following North West team members claimed gold in their respective sports and games: Dave Clark in Kurling; Dinesh Gorasia in Darts Sitting; Mike Griffiths

in Bowls; Muriel Bradshaw in Scrabble; and Dee Cartwright and Karen Pike in 5s and 3s.

Competitors arrived at the Leicester Marriott Hotel having qualified from the ten regional heats to compete across eleven games – Scrabble; Cribbage; Darts Standing; Darts Sitting; Bowls; Boccia Class 1; Boccia Class 2; Dominoes; Kurling; 5s & 3s and Draughts.

Eyes were focused on a few games in particular. Everyone was keen to see if Yorkshire's David Howells would continue his dominance of Darts Standing. David's remarkable record continues, as he claimed gold in the sport just ahead of Northern Ireland's Ronnie Connelly.

Northern Ireland's repeated attendance at the Games was once again welcomed with open arms by all of the other regions. Their presence at the Games means not only a great chance to catch up, swap stories



Medal winners with Dr Dirk Pilat FRCGP, Medical Director for e-Learning at the RCGP.

Top row, left to right: Paul Stanton; Eddie McCrory; Mike Griffiths; and George Riddell.

Bottom row, left to right: Glynn Lloyd; Pauline Henfrey; Joan Robson; and Wendy Lloyd.

and share memories, but made for another highly competitive Games.

As it was, the Northern Ireland team secured their highest ever finish in the Games, claiming third place overall. Alan Weir's gold medal in Boccia Class 2 confirmed this place, as did Joe McVeigh's silver in Boccia Class 1.

North West's Muriel Bradshaw claimed gold in Scrabble, with Scotland's Mary Guild finishing as runner-up. Third place meanwhile was once again snapped up by Chair of the Championship Committee of the Games, Christine Lumb, with fourth place going to East Midlands' Tom Copp.

In Cribbage, Yorkshire's Pauline Henfrey and Joan Robson claimed gold and silver respectively, whilst Western Region's Glynn Lloyd finished third, with Gaye Lockyer from Home Counties North securing fourth spot. As mentioned previously, David Howells from Yorkshire retained top spot in Darts Standing, with Northern Ireland's Ronnie Connelly securing silver.

East Midlands' Mike Poole, and Manfuzer Rahman from Home Counties North, made up third and fourth respectively.

Bowls once again proved a tense affair, with keen onlookers watching to see who would triumph. North West's Mike Griffiths claimed gold; North of England's George Riddell secured runner-up spot; Eddie McCrory from Northern Ireland claimed bronze, whilst Charles Raymond from Home Counties North finished fourth.

In Darts Sitting, Dinesh Gorasia finished first, with his North West teammate Tom Maddocks claiming runner-up spot. Western Region's Wendy Lloyd and Northern Ireland's Patrick Campbell meanwhile claimed third and fourth respectively. 🎯



Medal winners with Dr Dirk Pilat FRCGP, Medical Director for e-Learning at the RCGP.

Top row, left to right: Dinesh Gorasia; Tom Maddocks; Mike Poole; and Ronnie Connelly.

Bottom row, left to right: Jean Garness and David Heatherill; Bob Howell and Isobel McAneny; Sheila Barnes and Mo Page; and Brenda Stewart.

▶ National Vice-Chairman of The British Polio Fellowship, Aidan Linton-Smith secured gold in Boccia Class 1; Northern Ireland's Joe McVeigh claimed second; North of England's Mary Davison finished third, whilst North West's John Brear claimed fourth.

Boccia Class 2 was equally as exciting. Alan Weir from Northern Ireland claimed top spot; Westerns' Paul Stanton secured runner-up spot; Anna Tizzard from Scotland finished third, whilst North West's Bob McCarthy secured fourth place. In Kurling, North West's Dave Clark claimed first place; Fran Pratt from the North of England team came second; Northern Ireland's Jim Bailey secured bronze and Western Region's Julie Round finished fourth.

In Draughts, Andrew Gilliland secured gold; North of England's Barry Gower achieved silver; Brenda Stewart from Yorkshire finished third and Patricia Campbell from Northern Ireland claimed fourth spot.

When it came to the doubles sports, proceedings were just as intense. In Dominoes, North of England's Bob Howell and Isobel McAneny successfully defended their title from last year; Western Region's Sheila Barnes and Mo Page secured the runner-up spot; David Heatherill and Jean Garness from Wales finished third, whilst North West's Anne Hogarth and Eleanor Maddocks finished fourth.

In 5s & 3s, Dee Cartwright and Karen Pike from North West finished first; Ann and Dennis Kay from Yorkshire finished in second; Bill Burton and Mary Barker from Western claimed third place, and Glenda and Mick Collins from Home Counties North finished fourth.

You can see the full results table on page 14.

"I would like to congratulate the North West on successfully defending their title at this year's Games," said Ted Hill. "Once again, the Games proved a hard fought contest with an afternoon full of friendly competition. It's also a great event and opportunity for members across the country to meet up and socialise. Having the Northern Ireland team attend again was brilliant to see, and the fact that the attendance keeps getting bigger and bigger just shows how much the Games mean to people.

"A huge thanks must go to all of the officials who organised this year's event; the hard work they put in ensures the Games success every year, and this year was no exception. Chair of the Championship Committee, Christine Lumb, and the Games co-ordinator John Haddock put in a lot of work to ensure the day ran smoothly, so I'd like to thank them and all of the Committee and officials who made the weekend possible." **b**



Medal winners with Dr Dirk Pilat FRCGP, Medical Director for e-Learning at the RCGP.

Top row, left to right: Andrew Gilliland; Barry Gower; Jim Bailey; and Dave Clark.

Bottom row, left to right: Fran Pratt; Christine Lumb and her grandson Christopher Hill; Muriel Bradshaw; and Mary Guild.

Purple Hound update

Since the last edition of **the bulletin** we have had positive discussions with the Disabilities Minister, have the chance to potentially meet and discuss the idea with a key Number 10 official tasked with Accessibility, and have had contact with Dame Tanni Grey-Thompson. We also have an intern joining us from the USA shortly, for a couple of months via Bunac.



Cliff Haney will dedicate his time to Purple Hound among other Central Office marketing duties. We should know much more about the future direction of Purple Hound by the end of this year. In the meantime, we are still very interested in speaking to any contacts you may have that would be prepared to sponsor an App, an online members' portal and a printed directory, which is what this project essentially needs to get it off the ground.

Thanks to all members who took part in the creation of the Purple Hound video at the Leicester Indoor Games. The video was made possible by Lewis McMenamin, who completed the project alongside BeyondPR, as part of a 3rd year assignment on his degree course at Sheffield Hallam University. Lewis is pictured here with Ahmad Butt from Central Office, at the Games. The fruits of Lewis's work can be found online at the Purple Hound website: www.purplehound.org.uk



**PURPLE
HOUND**

ACCESS
YOUR
POTENTIAL

National Indoor Games Results 2017

SCRABBLE			CRIBBAGE		
4th	Tom Copp	East Midlands	4th	Gaye Lockyer	Home Counties North
3rd	Chris Lumb	Yorkshire	3rd	Glynn Lloyd	Western
2nd	Mary Guild	Scotland	2nd	Joan Robson	Yorkshire
1st	Muriel Bradshaw	North West	1st	Pauline Henfrey	Yorkshire
DARTS STANDING			BOWLS		
4th	Mahfuzur Rahman	Home Counties North	4th	Charles Raymond	Home Counties North
3rd	Mike Poole	East Midlands	3rd	Eddie McCrory	Northern Ireland
2nd	Ronnie Connelly	Northern Ireland	2nd	George Riddell	North of England
1st	David Howells	Yorkshire	1st	Mike Griffiths	North West
DARTS SITTING			BOCCIA CLASS 1		
4th	Patrick Campbell	Northern Ireland	4th	John Brear	North West
3rd	Wendy Lloyd	Western	3rd	Mary Davidson	North of England
2nd	Tom Maddocks	North West	2nd	Joe McVeigh	Northern Ireland
1st	Dinesh Gorasia	North West	1st	Aidan Linton Smith	Home Counties North
DOMINOES			BOCCIA CLASS 2		
4th	Anne Hogarth Eleanor Maddocks	North West	4th	Bob McCarthy	North West
3rd	David Heatherill Jean Garness	Wales	3rd	Anna Tizzard	Scotland
2nd	Shelia Barns Mo Page	Western	2nd	Paul Stanton	Western
1st	Bob Howell Isobel McAneny	North of England	1st	Alan Weir	Northern Ireland
5's & 3's			KURLING		
4th	Glenda Collins Mick Collins	Home Counties North	4th	Julie Round	Western
3rd	Bill Burton Mary Barker	Western	3rd	Jim Bailey	Northern Ireland
2nd	Ann Kay Dennis Kay	Yorkshire	2nd	Fran Pratt	North of England
1st	Dee Cartwright Karen Pike	North West	1st	Dave Clark	North West
DRAUGHTS			TOP REGIONS		
4th	Patricia Campbell	Northern Ireland	4th	North of England	
3rd	Brenda Stewart	Yorkshire	3rd	Northern Ireland	
2nd	Barry Gower	North of England	2nd	Yorkshire	
1st	Andrew Gilliland	North West	1st	North West	

Most attended Games ever

Following the enjoyable and captivating Games, the gala dinner on Saturday evening was a night of old friends catching up, new friendships being formed, great food and just one or two drinks enjoyed!

This year's trophies and medals were presented to the winners by Dr Dirk Pilat FRCGP, Medical Director for e-Learning of the Royal College of General Practitioners (RCGP). Speeches were enjoyed by all, with a great three course meal of the highest quality once again. Many members commented how great it was to see so many members of the Fellowship all together for one of the charity's most anticipated events of the year.

A record attendance for the Games was seen for the second year running at the Leicester Marriott Hotel. An amazing 235 people turned up for the weekend of Friday 17 March to Sunday 19 March, as either competitors, officials or helpers. We're sure you'll agree it's extremely encouraging to see the Games becoming more popular with each year that goes by.

"The Games is enjoyed enormously by everyone involved and is a fundamental part of our annual support to members," said Ted Hill. "It is the first date in

the annual calendar for both participating members, staff and helpers. Long may the popularity of these fantastic Games continue! A special note of thanks to Shirley and Kripen, all from Central Office, as well as all the volunteers who work so hard each year for many months to pull the Indoor Games together into the slick event we can all just turn up to and enjoy," Ted added. **b**



Forum reminder for Fellowship members

Following feedback from the Roadshows (which you can read more about on page 16), The British Polio Fellowship would like to remind members to use the charity's dedicated online forum. The forum is private, and exclusively for members of The British Polio Fellowship only.

The forum presents members with a great place to share stories, tips and experiences that can benefit other members who are in a similar position. By bringing members closer together, branches that are far apart geographically can help one another in an instant. Strength in numbers is a popular phrase that rings true, and the charity's forum reinforces this. A group of people will more often than not be able to help more than an individual, and on the forum The British Polio Fellowship has seen this prove true a number of times.

One of the biggest advantages of the forum, and one of the reasons it is so popular by the members who do use it, is that it's there as a talking point. Learning by talking can be a lot more powerful than just simply reading a book, website article or other piece of information on your own. By talking about an issue with other people in the same position, you can learn much more and realise aspects to your predicament that you would otherwise not have considered.

The forum is a great place to post questions about PPS and other Polio related conditions, so please do use it. It's a great resource for members, and overseen by a group of dedicated moderators who ensure information is quick and easy to find.

You can sign up for the forum here: forum.britishpolio.org.uk/smf/ and if you have any questions on the forum, please contact Central Office on 0800 043 1935. **b**

The magnificent seven:

Spring roadshows offer a roadmap for the future

The programme of roadshows concluded with the Watford event held at Bushey Sports Club on 31 May. Central Office and the Trustees would like to thank everyone who came along to the events, which will help shape the future of The British Polio Fellowship.

Starting in Leicester on 25 April, the show moved onto Gloucester on 26 April; Chester on 2 May; York on 3 May; Edinburgh on 8 May and Newcastle on 9 May; all were attended by a selection of local members and representatives of the Trustees and Central Office. The final roadshow, to be held in Watford will have taken place on 31 May, just before you receive this **bulletin**.

The first roadshow in Leicester got off to a great start, even attracting the attention of the local media, who sent a photographer to cover the event for an article in the Leicester Mercury. The results and feedback are now being digested by the Central Office team and the Trustees; results will be published in a future edition of **the bulletin**.

If you were unable to attend one of the roadshows, but still want to have your say, it is not too late; your views matter. The member's survey is still available on The British Polio Fellowship website and a hard copy was printed in the last issue of **the bulletin**. Alternatively, hard copies of the survey are available on request. **b**



Leicester



Gloucester



Chester



York



Edinburgh



Newcastle

Chairman's update



Firstly, many thanks to my fellow Trustees, Fellowship staff and members for their support and kindness during my recent illness. It is easy (as the late Bryan Rowley found) to think that PPS is the main culprit but never hesitate to see your doctor as with many of us, it turns

out, that our problems are something quite different requiring immediate medical treatment! Please, please write into **the bulletin** and share your experiences, your warnings, your tips and your advice. At some of the recent roadshows there was criticism that not enough member stories were published! The editorial team at BeyondPR can only print what they receive. Remember that **the bulletin** is also read by MPs, the medical profession and a host of decision-makers who regularly express admiration and amazement at what us Polio survivors have achieved.

One such Polio survivor was Lord Snowdon and I was lucky to be awarded (through the ballot) an invitation to his memorial service in April at St Margaret's next to Westminster Abbey. Over 600 people attended including a reported 53 members of the extended royal family led by HM The Queen, Princes Philip, Andrew and Edward and William. I managed to briefly speak to The Duchess of Gloucester (who opened Central Office office for us) and, more importantly, to Viscount Linley (the new Earl), and his sister, Lady Sarah Chatto. They thanked the British Polio Fellowship for being present and said that although their father hardly ever mentioned his 'horrible Polio years' there was no doubt that his experience kick-started his life-long fight for the disabled.

I was quite hurt by some of the comments (e-mails and on the forum) as to my lavish salary and allowance!! All the Trustees only receive their proven expenses (checked very carefully down to the last penny by our Finance Manager) and some Trustees do not even claim travel and return monies as Gift Aid! My trip to honour Lord Snowdon was made on a cheap senior National Express coach and a Tesco £3 meal deal! Genuine debate and criticism is the hallmark of a good organisation but please remember you do not shoot volunteers but constant sniping can drive us away.

Another upsetting subject has been the question of why we held the roadshows and produced the questionnaire in **the bulletin** (and on line) as to the future of the Fellowship. Surely, as Trustees it is our duty to consult the members and many of you asked to be involved and informed which Ted Hill does in every issue. The agendas for the Board Meetings in January, March and May and the two Finance Committees in March and May were very wide ranging and anything not reported in Ted's articles are mainly staffing matters, historic ongoing problems, European Polio Union affairs, fundraising, cash flow, investments, branch and regional updates, cost cutting (my speciality), future initiatives, national events, publicity and legacies etc. The subject of legacies is quite emotive, but we have been heartened by the result of the mail-out document 'Legacy Plea' and the excellent promises from members that the Fellowship is to be remembered in their Wills. Our big worry on cash flow it that accountancy rules state that any notified income must be booked immediately but can take up to two years to arrive! We do not receive any government funding, lottery funding is just that – a lottery and many superb Trust Funds regularly support us but, again, their reserves are dwindling. Donations and fundraising events from you, the members, are our lifeblood and the Trustees thank you all most sincerely. We are constantly looking for new revenue streams, eg. the wheelchair project, Purple Hound, letting the final part of the first floor at Central Office. Members at the roadshows have favoured introducing an annual voluntary contribution scheme (quite a few of you already do this) and a lady at the Leicester event and many at the Edinburgh and Newcastle shows, supported this idea with great enthusiasm pointing out that she paid just 7/6p for life membership and had the benefit of the work and guidance of the British Polio Fellowship for over fifty years! The roadshows have given us a better picture of your views, needs and concerns with some great ideas but remember, please, that in this commercial age, 'cash is king' in order to carry forward our work.

Once again, thank you for your work, interest and enthusiasm. Whether we are Trustees, regional/branch officials or just ordinary supporters, we are all Polio survivors together in fellowship.

David Mitchell
National Chairman

The Ron Scudamore Holiday Programme

The programme originated from a legacy made by our former Chairman, Ron Scudamore. Ron served as our Chairman in the 70s.

At one time Ron used to run the Western Region holidays and he always believed that it was important that members could enjoy affordable and accessible holidays. He wanted his legacy to be used solely for this purpose and so the Holiday Programme was born.

Since the programme began we have helped pledge over £180,000 to help people enjoy a much needed holiday or break.



Burnham Bungalow

Members looking for an affordable holiday in comfortable, well adapted accommodation overlooking the sea can enjoy a week at the charity's holiday bungalow. The bungalow offers well-adapted and modern accommodation and has the facilities to guarantee a good holiday at any time of year. The table shows the new weekly rates for the holiday bungalow. All bookings begin on a Saturday.

Please note that pets are not allowed at the bungalow unless they are certificated assistance dogs.

Grant applications

How it works

The maximum grant that you can apply for is £350 towards the cost of your holiday or break. You can holiday in this country or abroad and it can be used towards the hotel or flight. To request an application form or for further information please contact Rosalind Evans on 0800 043 1935 or email: rosalindevans@britishpolio.org.uk

Once we have received your application, it is considered at the next Grant Review Panel which meet every two months. Please remember to send your application in well in advance (see box below as to when to submit your application for consideration). After the Grant Review Panel has met you will be notified in writing.

Please note that your holiday departure date needs to be at least six weeks after the relevant panel meeting. Grant pledges are not paid retrospectively.

You can apply for a grant once every two years.

Applications Received	Review Panel Meets	Earliest Grant Payment
1 May - 30 Jun 2017	Mid Jul 2017	10 Aug 2017
1 Jul - 31 Aug 2017	Mid Sep 2017	10 Oct 2017
1 Sep - 31 Oct 2017	Mid Nov 2017	10 Dec 2017
1 Nov - 31 Dec 2017	Mid Jan 2018	10 Feb 2018

Dates for 2017	Price Per Week
20 May - 30 Jun	£574
1 Jul - 22 Sep	£600
23 Sept - 27 Oct	£474
28 Oct - 8 Dec	£337 reduced to £200
9 Dec - 29 Dec	£447 reduced to £200
30 Dec - 6 Jan 2018	£447 reduced to £200

Please advise at the time of booking if this is the case. We strongly advise that people staying at the bungalow obtain necessary travel insurance.

A deposit of £100 per week is required at the time of booking to secure the bungalow. To make a

booking please contact Rosalind Evans on 01923 281 097 or email rosalindevans@britishpolio.org.uk There are very few dates left to stay in the bungalow during 2017, so book now.

Burnham Bungalow spring clean up



Bungalow ready for summer

the bulletin would like to remind members of The British Polio Fellowship that the Burnham Bungalow is all set for visitors and holiday makers this summer. Those in the know use the bungalow on a regular basis, but The British Polio Fellowship would like to see more members make use of it. You can find out more information about the bungalow on the opposite page.

With facilities in place across the bungalow to help people with a range of disabilities enjoy their holiday with their families, the Burnham Bungalow is there to be used and with as much as £350 available from the holiday programme (details opposite) for those who need it, a holiday at the bungalow could be the ideal way to save some money and have a great holiday at the same time.

Members visiting the bungalow can expect to find hob and sink worktops that can be raised and lowered automatically, plus a bedroom with a hoist. Those who have visited in the past have commented on the great location and accessibility options that the bungalow presents.

There are also fantastic sea-front views, with accessible ramps down onto a private terrace with table and chairs. Lovely flower boxes line the terrace,

containing the 'Sowing the seeds of hope' wildflowers that our National Treasurer, Linda Evers planted back in 2014. The flowers continue to blossom every year, adding a lovely, vibrant touch to the bungalow.

Linda herself has championed the bungalow in the past, singing its praises and in the process encouraged other members to stay in it. As a regular visitor to the bungalow with her family, Linda knows better than most just how good the bungalow is.

Overall, the bungalow is a comfortable, well adapted and affordable holiday destination for members of The British Polio Fellowship. It is strongly advised that anyone staying at the bungalow obtains necessary travel insurance, and please note that a deposit of £100 per week is required at the time of booking to secure the bungalow.

Pets are unfortunately not allowed at the bungalow unless they are certificated assistance dogs, and this must be advised at the time of booking if this is the case. For more information on the bungalow, and how to book, please take a look at the Holiday Programme page opposite. **b**

the bulletin takes on a new format

It was agreed at the most recent Board meeting that the last issue of *the bulletin* (Spring 2017) would be the final issue printed on glossy paper. This decision was made after careful consideration by the Trustees, taking into account members' views and print costs.

As you can see from this issue of *the bulletin* that you hold in your hands, the outside cover has maintained a gloss look and feel, retaining vibrant colours and intense printed images, whilst the inside pages are now printed on matt paper. We hope this will ensure *the bulletin* still looks appealing. Matt paper offers no surface reflection and feels smooth and dull to the touch. Although the ink lift isn't as pronounced as gloss paper, with some images appearing slightly flatter, readability should be improved for most people.

The last decade has been a difficult time for the UK magazine paper manufacturing industry, with the sector undergoing considerable consolidation.

The number of UK production mills closing has increased while demand for print has also decreased; this is in part due to the emergence of new communication channels and significant price increases last year, which impacted on paper material costs by up to 33 per cent in some cases.

With this in mind, the correct selection and ongoing review of *the bulletin's* printing paper is more important than ever, to control publishing budgets and the Fellowship's funds. Switching the publication to a lower weight of paper will make all the difference to mailing costs and reduces the total amount of paper purchased.

We have listened to members' needs on this topic, but if after seeing the new type of paper in this issue you have any thoughts, please do let us know either here at Central Office, or by emailing thebulletin@beyondpr.co.uk **b**

Working with Rotary; Lions; Freemasons and other groups – a reminder

The British Polio Fellowship and *the bulletin* would like to remind members and branches of the charity to work with their local Rotary; Lions and Freemasons groups, as well as other organisations. Such groups are committed to helping charities and good causes, both in their local areas and further afield.

Rotary is a global network of over 1.2 million members who come together to make positive and long lasting changes to communities at home and abroad. Working with Rotary members connects you with a diverse group of professionals who share your drive to give back.

The Freemasons is one of the UK's top charities, raising over £30m a year for one of its main grant-giving bodies. Individuals give time and money to help others by volunteering on local community projects, making donations to other UK charities and responding to international disaster appeals.

This year, Lions Clubs International is celebrating its centenary. Every Lions Club supports a range of good causes and projects in its area, and you can get involved. Every year in Europe alone, Lions Clubs' members

volunteer around six million hours of service and raise £88 million to support the needs of local communities.

Working with these groups is invaluable; by sharing experiences, opinions, views, stories, information and resources, individually and collectively we can raise awareness of PPS in forums that are highly influential and potentially more receptive to our cause.

Don't forget that there are other organisations you can work with as well – if you know of any that you or anyone else works with, write in and tell us here at *the bulletin*.

We already have some great examples of Fellowship branches working closely with such groups. On pages 64 and 65 you can read how the Northamptonshire Branch of The British Polio Fellowship is working with the Wellingborough Hatton Branch of Rotary International, to great effect. Please contact Central Office if you have initiatives with Rotary, Lions or the Freemasons you'd like to inform us about, or if you have any ideas about how we can strengthen and develop these ties at local and/or national level. **b**

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Turkey

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Magnificent and inspirational!



Colin Powell, lifelong British Polio member and our Rotary Liaison Ambassador

On Sunday 5 March, The British Polio Fellowship's Rotary Liaison Ambassador Colin Powell delivered a 30 minute presentation to over 300 delegates at the Rotary District 1175 Conference in the South West of England, receiving a standing ovation for his efforts. Colin joined Rotary in 2009 and following his induction talk to his club, he was instantly invited to give motivational presentations at numerous Rotary District Conferences, Assemblies and other events.

Colin delivered his speech at the end of the One World Conference (3-6 March) held at the Atlantic Hotel in Newquay, Cornwall. Colin was joined at the event by Linda Davis from Central Office. The British Polio Fellowship had a stand at the event, and Linda was able to hand out information and publicity material about the charity and PPS to the hundreds of delegates in attendance.

Friday's agenda had a truly international flavour. Caroline Pover spoke about her work in helping those affected by the tsunami and earthquake in Japan back in 2012, while Faraday Fernside's focus was the Open Hearts, Open Borders charity which has been helping Syrian refugees; Elizabeth Gowing addressed conference about her work in Kosovo.

Saturday morning included a session on mental health issues with talks from the Invictus Trust, Claire Worden, Stephen Howard and Ian Sherriff; followed

by RSM Baz Gray of the Royal Marines who was part of the re-enactment of Ernest Shackleton's Elephant Island expedition. Martin Parnell gave an update on his work for Right to Play and investigative journalist and anthropologist-explorer Sarah Begum delivered tales of her adventures around the world, including living with an Amazonian tribe and helping survivors of Typhoon Haiyan in the Philippines. Colin rounded off the formalities of the conference with his talk on Polio, with a more light hearted closing of the conference provided by the entertaining Halifax Rotarian, Ken Robertshaw, who rowed down the Mississippi in 2014.

Colin's presentation, entitled Living With Polio, described how contracting Polio when just six months old was to have profound effect upon his life. The address covered how he managed to cope with and overcome the severity of his disabilities and is a damning indictment of life in the 1950s for those with Polio – the hopelessness and the challenges that had to be faced and fought. As shocking as the story is, Colin's strength of character and unflinching determination shone through as undiminished and his story had a profound impact on many of the hundreds of delegates listening in the hall.

Present to hear Colin speak was Rotary UK President Eve Conway, who on hearing Colin speak, nominated him as one of Rotary's Purple4Polio Ambassadors and

Colin wows Cornwall conference

represents another way for The British Polio Fellowship and Rotary to join forces on areas of mutual interest. In his now dual Ambassadorial roles, Colin is in a unique position to ensure the aspirations of both Rotary and the British Polio Fellowship are met in a way that ensures the success of both. Colin's greatest wish is to see Rotary's Global Polio Eradication Campaign succeed in order that tomorrow's world is free from Polio and that no child born in the future will have to experience a lifetime as a Polio survivor living with Post Polio Syndrome (PPS).

"This new role fits perfectly into the synergy of my current British Polio Fellowship mission as the charity's Rotary Liaison Ambassador," said Colin. "I believe this is a major step in bringing our two organisations far closer together and working in harmony for both Polio eradication and the ongoing support for UK Polio survivors."

Delegates were fulsome in their praise for Colin, realising quickly that while he may have lost the use of his legs, he has not lost his sense of humour. Colin gave a witty, yet very moving talk from the heart about his lifelong battle as a result of contracting Polio as a child and now living with Post Polio Syndrome. Many delegates remarked that it was a privilege to be in the presence of a Polio survivor, delivering an emotional account of the impact Polio has had on his life, and who is now coping with PPS.

"The presentation on Polio at District 1175 Conference was the best presentation I have ever seen on Polio," remarked one delegate; with another describing Colin as "a very courageous man," and another signing off with, "Well done Colin! You were magnificent and inspirational!"

"We all know Colin has been doing a lot of work behind the scenes in our relationship with Rotary and the results of his effort are now starting to bear fruit," said Ted Hill. "Our first ever PPS day in Winchester was run with support from the local Rotary club and shows what can develop from these relationships. Each organisation has a lot to offer the other and I'm sure we will continue to work together to our mutual advantage."

In 2016, Colin was invited by the Bill and Melinda Gates Foundation to participate in the making of a video entitled A Generation That Suffered Under Polio, to encourage politicians to support the One Last Push

global Polio eradication campaign. As always, while campaigning for the elimination of Polio worldwide, Colin is keen to see support for Polio survivors in the UK, for whom a vaccine has arrived too late and unfortunately don't have a cure for PPS.

Colin would like to remind all **bulletin** readers with Rotary connections that while he is happy to attend and address other regional Rotary District Conferences, regrettably, PPS impact levels now prevent him from travelling to and speaking at individual club meetings. Colin can be contacted at: colin@britishpolio.org.uk **b**



Launch of PPS centre

The European Polio Union (EPU) is proud to announce a new initiative with the launch of Post Polio Syndrome Centre for Life-long Excellence – known as **PoPSyCLE**.

PoPSyCLE is an initiative that has been set up to change the lives of Polio survivors, along with the perception of medical professionals for years to come.

One thing that has been very clear for many years, and has only been reinforced by the advent of social media, is the lack of training, knowledge and understanding amongst the medical profession, in general, to Polio survivors and those with PPS in particular.

Another fact is the increasing age range of Polio survivors in Europe, North America and Australia. Equally apparent is the increasing number of Polio survivors that have been identified in sub-Saharan Africa, the Indian sub-continent and other specific areas of the world.

It's been demonstrated that there are over 15 million Polio survivors, of which it is thought eight million are on the Indian sub-continent (the true total world-wide is probably more in the region of 28 million, and could be as high as 30 – 40 million).

When all these factors are put together, a picture emerges of the need to establish a facility to retain the existing PPS body of knowledge that is in danger of being lost in the so-called developed world. **PoPSyCLE** promises to be an internationally accredited training facility for medical personnel in the care, management and treatment of PPS – in association with an online support and exchange facility for Polio survivor support groups. **b**



Left to right: John McFarlane of the EPU, with Ted Hill at PPS Day 2016 in Stormont.

Trustees' elections

<i>Date</i>	<i>Deadline/event</i>
10 June	Nominations close
1 July	Postal ballot
19 August	Close of ballot
23 September	Ballot announced to AGM

Some of you may remember an article in the last issue of **the bulletin** (Spring 2017) on the upcoming elections. This is a reminder to all members wishing to vote that if you haven't received your voting papers, but believe you should have, please contact Central Office immediately.

Please be aware that you need to be a member of the company to vote and to contact Central Office if you have not done so already.

Three Trustees will stand down in September. David Mitchell and Mark Fisher can re-stand if they desire, however Linda Evers, having now served nine years, must stand down for at least 12 months.

Please refer to the table opposite for all dates on the elections.

Ted Hill

Notice of Annual General Meeting

The British Polio Fellowship AGM will take place on Saturday 23 September

Ramada Resort, Toll Bar Road, Marston (Grantham), Lincolnshire, NG32 2HT.



Agenda

10.00 Registration

11.00 Annual General Meeting including:

Annual Report on Year 2016

Accounts 2016

Election Results

Recommendations of the Board following feedback from the members survey and roadshows

Resolutions to the AGM

Questions to the Chief Executive

The Richard Flint Awards

Barbara Wood Awards

12.30 Lunch

14.00 Workshops

To be confirmed

15.30 Close

1. Please advise Central Office if you wish to attend the AGM as it helps with catering and saves money.
2. If you would like a copy of the Annual Report/Accounts in advance of the meeting please advise us at Central Office.

AGM Reply Booking Form

Please tick the relevant boxes.

☐ I wish to attend the Annual General Meeting, 23 September 2017, at the Ramada Resort, Lincolnshire.

☐ I am a member of the British Polio Fellowship and my membership is valid on 15 August 2017.

☐ I am a member of the Company (Only Company members are entitled to vote at the AGM). If you are not a member, contact Central Office to become one.

☐ Please tick if you want a copy of the Annual Report in advance.

I will be using my:

☐ Manual Wheelchair.

☐ Powered Wheelchair.

☐ Scooter.

NB: If you find you are unable to attend after you have returned the form, please contact Kripen Dhrona on 0800 0431 935 or kripen@britishpolio.org.uk. We have to pay for non-attendees if we do not cancel their places in advance.

Name

Address

Tel no

Name of guest(s)

(for Health & Safety recording)

Do you have any special dietary requirements (eg. gluten free, etc)?

☐ Yes

Please specify

Does your guest have any special dietary requirement?

☐ Yes

Please specify

Please return this form as soon as possible to: **Freepost, The British Polio Fellowship**

PPS Day 2017 confirmed for Scottish Parliament



Following the outstanding success of last year's event at the Northern Ireland Assembly at Stormont, it seemed fitting to host this year's PPS Day at Scotland's Parliament on 2 November 2017, to continue The British Polio Fellowship's tour of Britain's major political hubs to help spread the word on PPS.

Like Stormont, The Welsh Assembly and Westminster before, we hope you will agree the Holyrood building offers an impressive setting for PPS Day. The Parliament is located one km to the east of Edinburgh city centre, and sits at the foot of Edinburgh's famous Royal Mile in front of the spectacular Holyrood Park and Salisbury Crags. Constructed from a mixture of steel, oak, and granite, the complex building was hailed on opening as one of the most innovative designs in Britain today.

The Parliament building is a 15 minute walk from Edinburgh Waverley train station or there are a number of bus routes a short walking distance away so very accessible from all parts of the UK.

The main sponsor of the event from the Scottish Parliament is MSP, Alex Neil who is the member for Airdrie and Shotts, from the Central Scotland Region and is a member of the Scottish National Party (SNP). Alex's extensive experience working at local and national level means he will be an informed speaker

on the issues surrounding Polio and PPS as well as its impact on the people of Scotland and further afield.

The British Polio Fellowship is pleased to confirm that buildings across the country will be lit up in the colours of the charity once again to raise awareness of PPS Day. So far, the confirmed buildings are Gateshead Millennium Bridge, Newcastle; Spinnaker Tower, Portsmouth; Belfast Castle, Belfast; Inverness Castle, Inverness; Ness Bridge, Inverness; McCaig's Tower, Oban; The Clock Tower, Leicester; Edinburgh International Conference Centre, Edinburgh; Town Hall, Birmingham; and Grand Pier, Weston Super Mare.

If you have any other suggestions of buildings which can be lit up, or know of any contacts who can help the Fellowship, please let Kripen at Central Office know at kripen@britishpolio.org.uk

PPS Day contributes to The British Polio Fellowship's ongoing campaign to raise awareness of PPS with politicians and opinion-formers; the general public; and the all-important medical profession. Our focus remains centred on the importance of early diagnosis and the value of personalised care pathways to allow members to better manage the impacts of PPS in their daily lives. PPS Day 2017 in Edinburgh will further support members by increasing awareness of the condition north of the border in particular, as well as nationally in the UK. **b**

A sneaky peak into the future!

The hedgehog is coming – new British Polio wheelchair



The British Polio Fellowship is pleased to announce it will soon be selling its own electric wheelchair. The wheelchairs will be offered at a reduced cost to Fellowship members.

The aim is to produce a wheelchair with members' needs in mind.

It will be a lightweight model that also folds and opens in a matter of seconds and it is very compact for fitting into even the smallest car boot. Strain-free lifting is assured, as the wheelchair is so lightweight.

The wheelchair will be highly manoeuvrable around the shops but there is still plenty of legroom on board.

The hope is that the 'hedgehog' will eliminate the traditional concerns and problems that are commonly found in the bulkier and more expensive chairs.

There will be further updates on this in **the bulletin**. If you have any queries in the meantime, contact Ahmad at Central Office. **b**



British Polio 80th Anniversary

To celebrate our 80th Anniversary, Central Office would like to hear from you about possible event and fundraising ideas.

So far, considerations have included challenges such as an 80 kilometre sponsored walk, or an 80 minute sponsored swim. Any ideas that involve 80 repetitions, 80 activities or 80 members would be really nice and are great to get behind and support.

It would be good to have all the regions taking part in the events and celebrations.

Please send in your ideas to Kripen at Central Office at kripen@britishpolio.org.uk **b**

Members' tricks of the trade?

At one of the recent roadshows, Dawn from Central Office had a great idea we thought we'd share with you; it ties in nicely with calls from members at some of the roadshows.

So Dawn's idea is this: as members you must all have 'tricks of the trade', things you do, have seen or heard that help you or others get through the day, or overcome specific accessibility or health challenges. We want to know what you have done (and what you use) to adapt your lifestyle to the circumstances you find yourself in with late effect of Polio and PPS. For example, have you a neat way of opening jars more easily; do you have tips on how to get the best table at restaurants for your accessibility needs; are there any day-to-day shortcuts you have learnt, tips or tricks you can share with other members that make your life easier to cope with? We would love to hear from you at the usual address, thebulletin@beyondpr.co.uk or speak to Kripen at Central Office. **b**

Polio Profile - Franklin D Roosevelt

“We are going to make a country in which no one is left out. Physical strength can never permanently withstand the impact of spiritual force.”

Franklin Delano Roosevelt.

As the only US President to have served more than two terms of office, Franklin D Roosevelt was the highest profile proof that Polio doesn't have to define who you are.

Franklin Delano Roosevelt was born in 1882 in upstate New York. In 1916, the state was struck by the Polio virus which affected thousands of children and went on to infect Roosevelt himself. In the summer of 1921, when Roosevelt was 39 and a lawyer in New York, he went on holiday with his family to Campobello Island in Canada. After a day on the family sailboat with his wife and children, swimming in his favourite pond and racing his sons home, he complained of chills, nausea and pain in his lower back. He didn't eat and the chills continued through the night.

The following morning when he got out of bed, his right knee felt weak and he began getting a stabbing pain in the back of his legs. The GP in the nearby village diagnosed him with a bad summer cold, but by the afternoon his right knee would not support his weight and his left knee started weakening. A few days later, Roosevelt began to deteriorate; he was unable to stand, his legs were numb, his aches and pains became more severe and his fever continued. He could not pass urine, was unable to tighten the muscles of his buttocks or abdomen, and by evening his fingers became affected. By the following day he was paralysed from the chest down. A few weeks later he was finally diagnosed with Polio.

In 1922, due to tensions in the household, Roosevelt left his family in New York and went to live with his mother at Springwood. He bought a 71 foot houseboat and sailed to Florida with friends and a small crew. He believed that warmth and exercise would help rebuild his legs. He sailed for weeks, fishing and met with visiting friends. He designed a pulley system that lowered him into the water to swim. He also tried a range of therapies, and made two more voyages on his houseboat, but without improvement.

The following year, Roosevelt travelled to Georgia to visit the mineral springs where he became convinced of the benefits of hydrotherapy. He stayed at a resort in Warm Springs where he was able to retreat in comfort and get rehab for his legs.

Eventually he decided to buy the resort to turn it into a rehabilitation centre for Polio patients. One of his major goals was to get the American Orthopaedic Association to endorse the resort, but he was rejected because there was no real evidence of improvement in physical health.

He abandoned the project to focus on his next goal – to become US President! The resort is now the Roosevelt Warm Springs Institute for Rehabilitation, a comprehensive rehabilitation facility operated by the state of Georgia.

In 1929, Roosevelt was elected Governor of New York and moved into the Governor's Mansion in Albany. The mansion was made wheelchair friendly with ramps and an elevator before he moved in. He ran for President in 1932 and won in a landslide victory, becoming the first, and so far only, disabled person to be President of the United States.

Roosevelt was sworn in as the 32nd President in 1933. Before he moved into the White House, it was made wheelchair friendly with lots of ramps. Roosevelt, now known as FDR, didn't like the public to see him in his wheelchair. He avoided appearances by addressing the country through radio, and if he was shown on newsreels he used props to appear to be standing on his own. Pictures were taken at certain angles and at a distance to disguise his disability. FDR devised a method of walking in which he used a cane and the arm of his son or advisor for balance. He would manoeuvre his hips and swing his legs forward in a swaying motion to make it appear as if he was walking.

FDR became weaker towards the end of his presidency, and he found travel much harder to bear. He directed the nation through the Great Depression and World War II. In February 1945 he joined Churchill and Stalin in Crimea to discuss Europe's post-war reorganisation. A photo was taken of the three leaders, and out of respect for FDR, both Stalin and Churchill sat for the picture.


The President looked ill during this time and people questioned whether he was healthy enough to remain in office, but FDR's wife, Eleanor backed his ability to continue his presidency to the end.

Some have questioned FDR's initial reluctance to reveal his disability, but in the early 20th century people with disabilities were often looked down upon and hidden from the public eye. Many would have to be cared for by their family because companies would rarely hire them. FDR and Eleanor were instrumental in raising awareness and money for disability causes; he helped bring disability out of the shadows, and break down negative attitudes towards it.

Years after FDR's death, in honour of his legacy, the government installed ramps permanently in the White House, and made all federal buildings wheelchair-friendly. He also had his house in New York turned over to the National Park Service and made open to the public.

FDR threw huge parties so people could donate money enabling him to set up the National Foundation known as the March of Dimes, raising money for Warm Springs and Polio victims. The March of Dimes helped spread public awareness about Polio and its effect on those with the condition. His foundation is still around today and has expanded its focus to the prevention of birth defects and infant mortality, as well as the prevention of premature births.

Soon after FDR's death in 1945, his profile was used as the face of the dime coin, and remains on it to this day. He is rated, alongside Abraham Lincoln and George Washington, as one of the three greatest Presidents of the United States.

If you have a suggestion of someone living or from yesteryear that **the bulletin** can cover in its Polio Profile section in future issues, let **the bulletin** Editorial Team know at thebulletin@beyondpr.co.uk 



Christmas comes early for British Polio

In the last issue of *the bulletin* (Spring 2017), you may remember seeing the winners of the Christmas card competition. The cards are now on sale and can be purchased either by using the order form on page 30, or on The British Polio Fellowship website.

The cards can be purchased in a pack of 12, with three of each design in a pack. The price for a pack is £4.05. The deadline for purchasing Christmas cards is 6 December.

The under 16s Christmas card competition saw the following winners.

The star card was the iconic star labelled with words of the season such as joy, peace, light, love, thanks and hope. The star is one of the greatest Christmas symbols. The Christmas star has traditionally been associated with the spirit of the season and there is something very special about it. It decorates our homes, tables, trees and the garlands of our homes throughout the festive period.

The robin card featured the classic bird sitting on a branch with snowflakes falling all around. A firm favourite and undoubtedly a Christmas classic, the robin card was chosen as one that would be well received by the members as in the past. Robins have been traditionally depicted on Christmas cards since the beginning of the 19th century as its inspired by the British postmen who wore bright red uniforms in the 1800s. Around Christmas time,

people would eagerly await the Robins' delivery of Christmas cards from near and far. Our affection for the robin was cemented in 1960 when it was voted Britain's national bird. Christmas robins will forever be commemorated on Christmas cards and we hope will always be a common sight in our gardens.

The Christmas tree card included presents in the traditional red and green colours so widely associated with Christmas. The green represents evergreen plants, like Holly, Ivy and Mistletoe which have been used for thousands of years to decorate and brighten up buildings during the long dark winter. They also reminded people that spring would come and that winter wouldn't last forever. Red is the colour of Holly berries, which is said to represent the blood of Christ when he died on the cross.

Although there may not be much snow around in December, it is every child's dream to play in the snow and build a snowman on Christmas day. This was reflected in the snowman card. Probably the most famous snowman is 'Frosty the Snowman' who appears in a Christmas song of the same name. There is also the famous animated film called *The Snowman* (made in 1982) about a snowman who comes to life and takes a little boy flying off to see Father Christmas. **b**

Christmas Cards 2017

Pack of 12 cards (3 of each design) Size 155mm x 108mm - £4.05 per pack



British Polio Fellowship Christmas Cards

To Order

Choose the number of packs you would like to purchase and fill in the table below. Ensure you complete your full name and address in the delivery section.

The deadline for purchasing Christmas cards is 6 December 2017.

Item	Quantity	Cost per pack	Total
Pack of 12 cards 3 of each design		£4.05	
Subtotal			£
Donation			£
Total			£

Delivery Address

Name _____

Address _____

Postcode _____

Telephone _____

Email _____

How to pay

By Cheque

Please make cheques payable to The British Polio Fellowship

By Credit Card

[illegible]

Issue No

--	--

Expiry Date

☐

3 Digit Security Code*

Signature _____

*The Security Code is the last three digits of the numbers shown next to the signature on the reverse of your card. **THIS MUST BE GIVEN**

Gift Aid it

Using Gift Aid means that for every £1 you give, we get an extra 25p from HM Revenue and Customs, helping your donation go further.

I am a UK taxpayer and I would like to Gift Aid all donations I have made for the past 4 years prior to this year to The British Polio Fellowship and any I make in the future, until I notify you otherwise.

Signed _____

(To qualify for Gift Aid, what you pay in Income and Capital Gains Tax must at least equal the amount we claim in the tax year)

Your address is needed to identify yourself as a current UK taxpayer

giftaid it

Please post your order to:

Freepost
The British Polio Fellowship

Last Orders accepted 6 December 2017
Please allow 14 days for delivery

WHO urges Polio vaccine dose cut, amid global shortage

As The British Polio Fellowship joins Rotary and others in calling for One Last Push to eradicate Polio, efforts to beat the disease have hit a setback due to a shortage of the vaccine. Supplies are so low that the World Health Organisation (WHO) has urged countries to resort to smaller doses in the short term in the hope this will reduce the chance of outbreaks.

"We do have a problem with the vaccine in the sense of not having

enough of it," said Alejandro Cravioto, head of WHO's Strategic Advisory Group of Experts (SAGE). "But the recent evidence that we reviewed shows that even if we give a smaller dose of vaccine under the skin instead of inside the muscle, we can have the same impact of protection as before."

There have been reported problems in the production of the vaccine by the Sanofi and Serum Institute of India who make the main

Inactivated Polio Vaccine (IPV), but it is expected that stocks will be fully replenished by the end of 2018.

Cases of Polio have decreased by 99 per cent since 1988, when Polio was endemic in 125 countries and 350,000 cases were recorded worldwide. Today, the wild version now only exists in Afghanistan and Pakistan, where eight cases have been recorded in the past six months. [b](#)

Pulse Polio vaccination in 43,000 booths throughout India

While stocks of vaccine were reported as running low, the Times of India reported that as part of the second round of the nationwide intensified Pulse Polio immunisation campaign, over 43,000 booths had been set up by the state government on 29 April.

These booths were located in hospitals, child development service centres, noon meal centres, schools and other major locations. While children below the age of five were given the Polio vaccine in the first round of vaccinations on 2 April, these booths will catch others, while 1,652 transit booths will cover remote areas and children on the move. [b](#)



UAE commits \$120 million to eradication programme

In what is being seen as a positive step, the United Arab Emirates (UAE) has committed itself to the cause of Polio eradication with an additional pledge of \$120 million towards fighting the disease. The pledge follows the \$100 million support for WHO initiatives back in 2011 and underlines that the UAE recognises the unique role the country can play – not just in terms of financial support, but in the special relationship it shares with the countries in the Muslim world (Pakistan in particular) to ensure children in remote regions are vaccinated successfully.

The news came at the start of World Immunisation Week and while levels of transmission of the virus are now the lowest in history, no-one is complacent. It is recognised that the virus can move with mobile populations (particularly across borders) and this makes eradicating the virus difficult. It is able to 'hide' in unvaccinated children and then re-emerge with a vengeance.

These new funds will be vital as the WHO takes steps to reduce this happening.

International co-operation is crucial in the battle to beat Polio and Afghanistan and Pakistan are working hard to show that borders do not have to be a barrier preventing Polio immunisation. Both are working together in attempts to make sure no child, either side of the border can fall through the cracks.

There is still some way to go, with Christopher Maher, a manager working on Polio Eradication and Emergency Support within the World Health Organisation (WHO), talking of a significant funding gap estimated at one and a half billion dollars that still remains to be filled: "The fight has been going on for the past 29 years and we hope it can come to an end in the 30th year," said Chris. "If we can fill this funding gap, we hope that we can certify the eradication of Polio three years after the last case." **b**

Polio vaccine pioneer dies at 96

One of the pioneers of the Polio vaccine, Dr Julius S Youngner, died at his home on Thursday 27 April. Dr Youngner was 96.

Youngner's interest was infectious diseases, but the brilliant scientist was drafted into the Army in 1939 to work on the Manhattan Project where he studied the effects of uranium salts on the human body. In 1949, he was recruited to the University of Pittsburgh – to assist Jonas Salk's team in the development of an effective Polio vaccine.

As one of the world's pre-eminent virologists, his contribution cannot be overstated, as applying his methods, not least developing techniques for large scale production of virus raw material led directly to vaccine viability. He was also a champion and pioneer of testing and government licensing before allowing drugs to market.

While not as famous as Salk or Sabin, his work was important in Salk coming forward first with a proven vaccine for Polio. **b**



Polio survivors down under warn of threat of not vaccinating

The Sydney Morning Herald of 30 April covered the story of Christopher Tia, who alone of his two brothers contracted Polio – because they had run out of vaccine in Laos, prior to his family emigrating to Australia.

His case highlights the importance of having sufficient supplies of the vaccine and the need to contain the virus by maintaining high vaccination rates domestically and internationally – Australia was only declared Polio free in 2000.

“So long as Polio remains anywhere, it is a threat everywhere and Australians should continue to immunise against Polio and other diseases, even those that are rare to Australia,” said Michael Sheldrick of Global Citizen, leader of a delegation visiting Australia to call on the Australian government to increase funds to the WHO global Polio eradication initiative.

“We are in a race against time. There are still thousands of children who have never been reached, and all it takes is one case in an area with many children, and it can spread like wildfire.”

The impact of Polio, even mild cases, lasts a lifetime, as members of The British Polio Fellowship are all too familiar with. Many of the 400,000 Australians who contracted Polio before vaccines were introduced in the 1950s are now living with PPS; here in the UK, there are also many young Australians like Mr Tia who got the disease overseas.

In words that will resonate with members, Gillian Thomas of Polio New South Wales, who contracted paralytic Polio as a baby of 10 months old, said: “Eradication won't be the end of the story. Polio survivors both here and abroad are the ‘forgotten generations’ who are now experiencing the late effects of Polio and PPS – every last adult affected must be supported.” [b](#)



Oz Polio news update

It is interesting to compare the work our opposite numbers at Polio Australia are doing in the fight to see support for those with PPS. Our summary of some of the comments from their own newsletter Polio Oz News gives an indication of how the two organisations have taken a very similar approach in the fight for greater awareness of PPS.

President, Dr John Tierney points out in the March 2017 issue that Polio Australia has been lobbying the federal government for eight years for recognition and support for Australia's 400,000 Polio survivors.

Just as The British Polio Fellowship has pursued government channels with the help of our Parliamentary Ambassadors, including Rehman Christi, Polio Australia has six cross party Parliamentary Patrons.

One item Dr Tierney pointed out is, "One of the great things about lobbying is that if you stick with it long enough, the cards just sometimes fall your way." As Polio Australia has been working on its campaign for eight years, The British Polio Fellowship is not far behind and we are making significant progress. PPS Day in the UK is now approaching its fifth anniversary, as we prepare to visit the Scottish Parliament in November.

Likewise, Polio Australia has also looked to raise the profile of Polio survivors through campaigns like Walk with Me and We're Still Here. Much of this resonates with our own Sowing the seeds of hope and PPS Day campaigns and Chairman, David's Mitchell's comments that, "Polio may be dead, but we are not".

We wish our opposite numbers down under every success in raising the profile of Polio and PPS.

Invisible Disabilities

OZ Polio News reported on 'Invisible Disabilities' and that people with PPS can get accused of wrongly using a disabled parking space when they are perfectly entitled to do so. As **the bulletin** has run articles concerning Blue Badge misuse in the past, we thought the Australian take on this issue would interest members.

Have you ever seen someone who looks perfectly healthy using an accessible parking space? Did you assume that they were cheating the system? Did you know that many disabilities are invisible and have no obvious external signs? We've all seen the international symbol for disability printed on every accessible parking space. It's a little blue stick figure in a wheelchair, showing everyone that a space is reserved for people with disabilities. The only problem is, not everyone with a disability looks like that stick figure. Very few of us are blue, not all of us use wheelchairs and many of us don't look disabled at all.

People with invisible disabilities often face harassment and discrimination from people who assume that they are using accessible parking illegally. This harassment can cause serious distress to people living with a debilitating illness.

An invisible disability, as the name suggests, is a disability that cannot be easily seen by others. Although they may appear able bodied at first glance, people with invisible disabilities often live with symptoms like pain, fatigue, balance problems, cognitive or mental dysfunction and vision and hearing impairments. Some invisible disabilities fluctuate, meaning that someone may be able to walk one day, but require a wheelchair the next.

People with invisible disabilities can require Disability Parking Permits for many reasons. Accessible spaces are located close to facilities, this allows shortened walking times and access to hired mobility scooters and wheelchairs. It avoids exposure to heat, cold, and exhaust fumes and allows people to use their limited energy on their chosen activity, not on getting to and from the car. The close proximity of accessible parking also limits exposure to hazards such as traffic and uneven footpaths. Accessible parking spaces are also wider than average, allowing extra room for people with limited or unpredictable movement, or who need assistance to get in and out of the car.

The discrimination and abuse suffered by people with Invisible Disabilities is widespread. In January 2016, Tasmanian Steven Maksimovic reported being harassed six times over a three-month period for using his Disability Parking Permit in and around

Hobart. Some of these confrontations caused distress to Maksimovic's six-year-old son who witnessed the events.

In November 2015 Victorian woman Justine Van Den Borne, who lives with Multiple Sclerosis (MS) caused a storm on social media defending her right to a use accessible parking after she found a nasty note taped to her windscreen saying "Did you forget your wheelchair???" Justine responded to the anonymous note on Facebook, saying "On the day you saw me I was having a good day. I was walking with my daughter unaided having a nice day. Thank you for ruining that. You made me feel like people were looking at me, the exact way I feel when I can't walk properly. I am sick of people like yourself abusing me on my good days for using a facility I am entitled to."

Although these are extreme examples, people with invisible disabilities often face more subtle forms of discrimination when parking. These might include being stared at, or hearing people make rude comments about them under their breath. Discrimination can have very real effects on the lives of people with invisible disabilities, making them feel self-conscious, unsafe or guilty for using the facilities that they are entitled to. These feelings can in turn lead to an unwillingness to go out, increased social isolation, anxiety and depression.

Australia has strict regulations outlining who can hold a Disability Parking Permit. Permit holders have all completed detailed forms that have been authorised by their doctors and approved by their local council. Displaying a Disability Parking Permit is proof that a person is eligible to use an accessible space, no matter what they look like. Check the following website for details: www.bluebadgeinsurance.com.au/new-national-disability-parking-permits-designed-help-reduce-fraud/

People without disabilities are also legally allowed to park in accessible parking spaces if they are stopping to pick up someone who has a disability. In this case, they must display the Disability Parking Permit of the person with a disability. Remember, not everyone who is eligible to use accessible parking is obviously disabled. Anyone displaying a permit has already proven their eligibility and demanding further proof is harassment. Do you have an invisible disability? Have you ever been harassed or felt unsafe while parking? There are a few things you can do to protect yourself. If someone confronts you, do not

engage or argue with them. You do not have to tell them anything about your disability; that is private information between you and your doctor. You may wish to make a short comment like "I have a legal permit".

If you are followed or harassed, make your way inside to the nearest building. Explain your situation to a staff member and, if necessary, ask them to call security or the police. If someone leaves a nasty note on your car, be sure to take a photo of it to provide proof of what happened.

Finally, if you repeatedly face problems in a specific area, you may like to raise awareness of the issue by contacting your local newspaper. Many people misguidedly think they are helping disabled people by calling out parking 'cheats' and may reconsider their actions once they realise that invisible disabilities exist.

Editor's note:

There have been numerous reported cases in the UK similar to those in this article – like the Royal Marine, Cassidy Little, who was abused for parking in a disabled parking space – the abuser presumably didn't realise Cassidy had lost a leg while serving in Afghanistan.

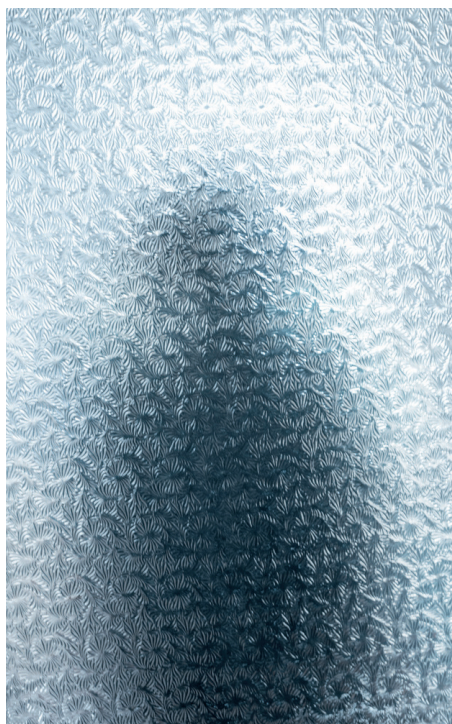
If the abusers concerned are so confident of their accusations, you would think they would be prepared to leave their name and details – isn't it odd that all the nasty notes and abuse are invariably anonymous, no matter where in the world it takes place?

The automatic assumption seems to be if you have a badge but are not visibly disabled; you must be a cheat. Many members of the British Polio Fellowship will know that it is far from easy to get a blue badge – the form, the medical evidence, then submitted to the local council for assessment.

Is your PPS treated as an invisible disability? Write into the usual address and let us know your thoughts and experiences. **b**

Polio pictures tell 1,000 words

International Polio perspective from Azerbaijan



Hello. My name is Ehtiram Jabi. I'm 21 and I'm a photographer, living in Baku, Azerbaijan. When I was two, I contracted Polio and received treatment for many years. But all these years have been a traumatic experience for me and persecute me. To get rid of them, I made a photo project related to Polio and I want to show it to you.

I fell ill with Poliomyelitis when I was two years old. Exactly on the day of my second birthday, my condition worsened and in a few weeks I had to go to the hospital. At that time in our country, few knew about this condition and the hospital was small and old. At first, I would go four times a year, then twice, and then once a year. At the end when I went once a year, I would go for a whole month. I was treated in this

hospital every summer for more than ten years.

If you ask me to talk about my childhood summer memories, the first things that come to my mind would be dirty hospital rooms, doctors working there, painful treatments and eternal despair. That unbearable despair is able to conquer all my thoughts and feelings.

Even though the physical pain I'd endured started to fade away from my mind after some period of time, Polio caused hardships and those miserable memories are still alongside me throughout my life.

These photos are the mirrors reflecting my soul – mirrors that reflect myself.

As I mentioned, I received my treatment during summer. While all of my friends were having fun during the most enjoyable time of the year, I'd get treatment procedures including everyday injections, massage, physiotherapy and being wrapped in hot tissues with paraffin. I hated the paraffin treatment the most. In the summer it gets very hot, and in this heat, lying for 20-30 minutes wrapped in hot cloth was very unpleasant.

I remember that, because of flat feet, I always had problems with shoes. Once I was ordered a pair of special shoes; they were heavy and black, like a soldier's boots. They were terribly uncomfortable to walk in and they looked ugly – at school, everyone laughed at me.

Since childhood, I've been in love with football, but because of Polio, I could not play as I wanted. I always had to take care of my foot, so I always watched from the window as other children ran after the ball.

Despite the fact that my memory is not very good, I can vividly remember the faces of all the nurses who were in the hospital. I remember the rooms, I remember the patients who were treated with me, I remember which way we went to the hospital, what procedures were in place and I remember even certain conversations of doctors.

I was lucky that, upon learning of my illness, my parents quickly began to treat me, and I had almost no physical problems. I only occasionally limp, but it is still difficult to choose shoes and I can't walk fast.

Most of my Polio affected me psychologically. I lost my childhood,

the most beautiful time of my life. I lost my dream of becoming a football player, or doing other sports.

This illness is like a scar in my life – it does not torment me, but it's not beautiful either.

Nowadays, I am a student, studying tourism. I am predominantly interested in photography, and have been involved in art since 2013. My passion in photo journalism has enabled me to partner with Reuters and some Azerbaijani services where some of my work has been published.

I had a photo series called 'On the top', 'White swan', and 'Veterans' released in leading local portals too. In 2014, I participated in the Yarat Summer School with Magnum Photography. David Montgomery plays a major role in my work. In 2015, during the exhibition 'Friendship of Peoples' in Moscow, I was invited to speak at a creative

meeting, and in the same year received a prize from the Union of Photographers of Azerbaijan Award 'Hope'. In 2017, I finished work on my first fully fledged project, 'Polio'.

You can see my photo project on Polio here:

yadi.sk/i/3h_X8vRi3G5rvq 



Travels with My Wheelchair

Part 16 - Stress - what stress?



It's generally accepted that there are three events which are likely to cause an increase in a person's stress levels – marriage, death ... and moving house. Now, I have lived in the same flat for nearly 30 years, and to be honest, moving was the last thing on my mind.

That was until late last year when I received a letter from my local council to say that they were going to be voting in a matter of days on a regeneration project which would affect the block of flats I was living in – and the others in the complex – some or all of which might be subject to demolition. Not really what you want to hear a month or so before Christmas. I expected a further letter to inform me of their decision in due course.

Within a couple of weeks, a housing officer appeared at my door with a housing application form. Yes, the project had been passed and my home was set to be demolished. Now some serious decisions had to be made.

Due to the demolition, I was automatically at the top of the housing list for a new flat or house in whichever area I wanted. Sounds ideal you might think, but just where did I want to go? I've always lived in a flat, but in the last few years I've had some less than pleasant neighbours – loud music played all the time and noisy parties every weekend. Eventually it got so bad I called the police as I couldn't climb the stairs to complain in person.

When the housing officer returned to collect the form, I picked her brain about areas of the town which might have been suitable – that is, accessible accommodation. I'd already had a chat with my cleaner about where I might like to move to (her mum was in the same position, but not being dealt with at this stage). She asked me if I could move anywhere in the town, where would I like to go? My answer was easy – the nice new houses down in the heart of the town on the site of what had once been the council offices. These houses, and they are houses,

not flats, are only a couple of years old and looked really pretty. However, I had no way of knowing if they were at all accessible, and to be honest, I didn't think I would have much chance of getting one of them.

On the Thursday before Christmas, I got a call from another member of the Housing Department team asking if he could call. Within minutes, he was at my door, with the offer of a new house – one of the new ones I really liked! I couldn't believe my luck. I wanted to see inside it first, of course, but this would have to wait until the new year.

I was both excited and scared in equal measure. I couldn't see how I was going to be able to pack up everything in my flat and get it to the new house.

Anyway, perhaps it wouldn't suit. Well, it almost didn't. A lovely house in all respects, except one rather important point; the bathroom was a bit of a nightmare.

As the house was built to be accessible, you would assume that it had a full wet room – unfortunately not. Instead it had a relatively flat shower base, with full height glass doors which opened on two sides, from the corner. Each of these doors could only open so far before they came up against other bathroom fittings and they didn't stay open. Definitely not user friendly. As this was the only problem with the house, the housing officer undertook to see what could be done to remedy the situation.

Several phone calls over the next week, various options discussed and then finally the decision I wanted to hear – they would install a full wet room. Several weeks of silence followed and I was in limbo. I couldn't do anything to organise moving as I didn't know how long it would take to get the wet room installed – council budgets being what they are.

Finally, at the end of February I got the long-awaited phone call. The house was ready. On 1 March, I signed the lease and then the panic set in – how to organise a move. I couldn't have packing boxes lying around as I needed to still be able to move round the flat in my wheelchair, and I couldn't lift heavy things down to put in the boxes in the first place. I certainly couldn't transport anything down to the house in the same way as I did the last time I moved.

However, I started off well. New carpets and furniture were ordered and delivery was arranged closer to my moving date. Gas heating was commissioned on 2 March, but several hours hanging around waiting on a gas engineer led to a rotten head cold – not what you want when there's so much to do.

Things went downhill quickly as stress levels rose over the next couple of weeks due to malfunctioning smoke detectors. These were faulty and kept going off. The council were reluctant to replace them, but eventually due to the involvement of the police and fire service, they were all replaced and silence now reigns. I still can't quite understand why a single storey house with only two bedrooms needs to have five alarms. Organising work to be done in the right order before the move itself was a bit of a nightmare, but I managed to get there in the end.

It's now two weeks on from the move itself and I've largely settled in. There's still a large hill's worth of boxes to be unpacked in my craft room. I've got a real conundrum there, with boxes stacked all over; how do you sort the box contents onto shelves when all the shelves and the floor are covered in boxes? I'll find a way, I'm sure, and I may even share it with you all – eventually. In the meantime, it's back to the unpacking!

Georgina Hay

Paisley Branch



Successful fundraiser at West Herts College

The British Polio Fellowship is delighted to report that the fundraiser organised by West Herts College, which took place on 29 March at the college itself, was a huge success, raising £340.85 for the Fellowship.

The chosen theme for the event was 70s disco, with the menu designed with the theme in mind. As a result, the food was classic of the decade. There was a drinks reception which was followed by a three course meal. The Level 2 Professional and Culinary students delivered the three course menu – and what a success it was!

As well as selling tickets for the event there was a raffle. Prizes were donated from a wide range of sources and all contributed towards raising funds for British Polio.


“This was the first year for this event, and we could not be more pleased with both the attendance and the generosity of the attendees,” said Diane Ware, Fundraising Co-ordinator at The British Polio Fellowship. Diane offered advice in the lead up to the event.

“Not only are we grateful to the West Herts College for organising this event, but we’d also like to thank everyone that came along and donated,” said Ted Hill.

“It was a huge undertaking to organise this event, with a lot of time put into planning the theme, deciding on the menu and ensuring the smooth running of the evening from start to finish, something which the college did flawlessly.”

Attendees commented that it was particularly nice to have students so engaged with the work of The British Polio Fellowship.

This was the first time the West Herts College had put on the event and the organisers have said they are already planning for next year.

The British Polio Fellowship is extremely grateful to the West Herts College for its generosity. If you, or anyone you know, would like to help the charity, either through a donation or by planning a fundraising event such as this one, then please contact Diane at Central Office on 01923 281 091 or by emailing diane@britishpolio.org.uk. You can also contact Kripen Dhrona on 01923 281 098, or by emailing kripen@britishpolio.org.uk 



In memoriam

<i>March/April</i>	<i>Region</i>	<i>Member</i>
Mr Michael John Jarvis	Warwickshire	Yes
Mrs Dorothy Capewell	Staffordshire	Yes
Mr Harry Booth	Merseyside	Yes
Mrs Anne Jones	Glamorgan	Yes
Mrs Wiltshire (mother of member)	Warwickshire	No
Mr Brian William Dendy	West Sussex	No
Mrs Dorothy Crook	Hereford	Yes
Mrs Ruby Hardy	Essex	Yes
Mr John Legard	London	Yes
Mrs Doreen Harris	Sussex	Yes
Mrs Edith Littler	Hertfordshire	Yes
Mr Rex Edward Rogers	Somerset	Yes
Mrs Margaret Radford	Leicestershire	Yes
Mrs Ann Stonebridge	Essex	Yes
Mr Howard Melville Davies	Neath	Yes
Mr Rodney Fuller	Hampshire	Yes
Mrs Elsie Emily Price	Cambridgeshire	Yes
Mr Norman Embleton	Not known	No
Mrs Dawn Varma	Hertfordshire	Yes
Mr David Butler	Kent	Yes
Miss Anne Ure	Falkirk	Yes
Mrs Dorothy Ashman	Bath	Yes



Thank you to everyone who has made a contribution in their memory. If you would like to make a donation in memory of a loved one, please contact Linda 0208 836 3689 or email: linda@britishpolio.org.uk

We would like to offer our sincere condolences to the families and friends of the above people.

Donations from Trusts and Foundations

The following Trusts and Foundations have generously supported The British Polio Fellowship over the first few months of 2017. It is with thanks to their support that the charity is able to continue with the services provided to our members.

Relief Chest Scheme

Rest Harrow Trust

IBB Charitable Trust

Bruce Wake Charitable Trust

Rind Foundation

Watford Council

Gamma Trust

Sydney Black Charitable Trust

Julia Mary Wood Charitable Trust

Fitton Trust

Lady Hind Trust

Hillcote Trust

Sobell Foundation

Yvonne Flux Charitable Trust

Daniels & Houghtons Charity

Unleash your inner Superhero!

British Polio team members sought for 19 August event

The Superhero Series, a triathlon event, is taking place on 19 August at Dorney Lake and is the first event in the only sports series dedicated to the UK's 12 million people with disabilities and long-term injuries – the Everyday Superhero. The Superhero Series allows disabled and non-disabled people to take part in triathlons - either solo, or in a team.

Home of the 2012 Paralympic and Olympic rowing events, Dorney Lake's clean, tranquil waters, level gradient and closed tarmac roads make it a natural choice for the debut event. There's plenty of free on-site parking and set in 450 acres of scenic parkland, it's a rather lovely day out for Superheroes, Sidekicks and spectators alike.

Anyone can take part as long as at least one member of the team considers themselves to have a disability. All you have to do is decide who's doing which stage/s. Team members are welcome to bring a Sidekick to push, guide or keep them company free of charge.

Superhero Series founder and Paralympian Sophia Warner explains why she started the Superhero Series initiative.

"As a person with a disability looking to do sport for fun I've found it a real struggle. I know what a positive impact sport can have on a person's life – I believe everyone should have the chance."

World Championship medallist Sophia added, "The idea is simple: to create fun, gutsy events where people with disabilities call the shots and don't have to worry about cut-off times or equipment restrictions. If you need flippers or floats in the water, or want to use your powered wheelchair, we make it possible."

Superhero Rashmi Barker from Telford, is taking part in the Sprint Sidekick Tri. This is a 150m swim, a 3k bike ride and a 1k run. Rashmi said, "I had Polio and wear a full-length calliper, which affects my mobility. It will be a challenge moving from one stage to another quickly and doing all three in one go!"

"When I was younger I swam for Bradford in the Polio Olympics and won gold medals at Stoke Mandeville. I still swim as much as possible and can do up to 32 lengths. In 2016 I joined a charity that encourages people with




disabilities to go cycling. My last big ride was 152 miles Coast to Coast over three days. I won the Woman of the Year Award in Lancashire for inspiring people and raising over £2,000 for charity. I also play table tennis and visit the gym as much as my health will allow."

Rashmi is the Team Captain of her team of six who are being sponsored by Quest 88. As well as sponsoring the event, Quest 88 will be providing equipment for hire such as tricycles, walkers, specialist tandems and RaceRunners.

In addition to the teams made up of the everyday Superheroes there is the Celebrity Superhero Competition. It is run over the same distance as the Sprint Sidekick Tri. More than 20 Celebrity Team Captains from Paralympians to TV personalities are taking part. There's a competition for members of the general public to get a spot on one of two remaining celebrity teams, either with Susie Rodgers, Paralympic swimming champion, or Chris Jones, World Championship surfing medallist and Help for Heroes ambassador. Details on how to be in with a chance are on the website as per the link below.

If you don't want to take part but still want to be involved then there is an open invitation to everyone to come down with your megaphones, banners and flags to cheer the Superheroes over the line. Plus, parking at this spectacular venue is free of charge.

From all of us at The British Polio Fellowship, we wish Rashmi, her team and all the participants the very best of luck and we eagerly await the results!

For information about the event, please visit superheroseries.co.uk/ and don't forget to follow the team on social media. 

Giving By Text

You can always make a donation to The British Polio Fellowship from your mobile phone, just follow these simple steps:

Text: BRPF39 £ (amount you wish to donate), maximum amount of £10.

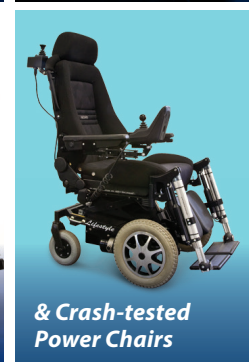
To: 70070 It's as simple as that! The amount you have donated will then be charged to your mobile phone account. **b**

Give As You Live

As The British Polio Fellowship is registered with Everyclick, when you do your online shopping at selected stores, around 3-4 per cent of the cost of your total shop will be donated to The British Polio Fellowship.

In some cases this could be more as the amount is dependent on the discount that has been agreed with the supplier. There are over 3,000 stores participating in this scheme, such as John Lewis, Waitrose, M&S, Amazon, Debenhams and many, many more.

All you have to do is visit the website www.giveasyoulive.com and start shopping. But don't forget to nominate The British Polio Fellowship as your preferred charity. **b**



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www.steeringdevelopments.co.uk

MOBILITY SPECIALISTS • HEMEL HEMPSTEAD



PPS self-management programme at St Thomas' Hospital - my experience



In November 2016, British Polio Trustee, Bosik Gharapetian, attended the PPS self-management programme at St Thomas' Hospital. What follows is Bosik's account of the programme.

I attended the Post Polio Syndrome (PPS) self-management programme at St Thomas' Hospital over a two week period in November 2016. This programme is multi-disciplinary and is led by an occupational therapist and a physiotherapist. It includes input from a psychologist, a psychiatrist, consultants from the Lane Fox Unit, a dietician, a representative from The British Polio Fellowship and the Chairman of The British Polio Fellowship Expert Panel.

The programme was aimed at self-management of the symptoms associated with PPS, mainly fatigue, new weakness and pain leading to loss of endurance and function. It is not possible to cure or resolve these symptoms but the aim of the course was that some of the skills and information included in the course might help improving lifestyle balance and reduce peaks and troughs of activity common to those with PPS. Included in the programme was relaxation, pacing and prioritising, a workshop on thinking patterns and challenging those negative thinking patterns as well as coping strategies

for long term conditions, communication styles, pain management, and exercise and dietary advice.

On the first night at the dinner table I met some interesting people who live with PPS; they came from various parts of the UK. They all had their interesting stories to tell especially how difficult it has been to get their GPs to diagnose their PPS condition and more importantly to refer them to a specialist who would understand PPS and support them in further diagnosis and management of it. I would say the few I met were the lucky ones who had taken the long journey from their GP's surgeries' to attend the well sought after and packed course at St Thomas' Hospital.

The course had been divided into two blocks of three days over a period of two weeks with a break in between to allow the attendees to get back home, rest and do some homework and reflect. The course was well designed to include both theory and practical sessions. The topics covered ranged from fatigue management to a session in the Hydrotherapy pool. The presenters were all well informed and conducted interactive presentations. The presentations were directed to the needs of the attendees who were encouraged to participate in the discussions.



Although at the end of each day formal sessions were finished, the PPS discussion did not. We continued discussing our experiences with PPS over the dinner table and any opportunity which we could find to share our experiences on how much Polio and now PPS has affected our lives. Behind every attendee's Polio and PPS experience there was a heart-warming story full of challenges, triumphs, hope and the positive attitude that "my condition is not going to stop me from doing the things I enjoy".

I commend these people and I personally benefited from the course and my interaction with the attendees and the presenters.

November rain and cold did not dampen the interactive and enjoyable classes. All this down to the participants and the dedicated staff and clinicians at The Lane Fox Unit looking after us. With the lodge/hotel across the building where I stayed for the six nights it was a very short walk to

get to the main building where the classes were being held.

At the end of the two weeks and six days of being together I was glad that I was going home but sad that I may not see my co-attendees from whom I learned so much. The good news is that we have exchanged contact details and we will keep in touch and continue to share our experiences as we go through life and put into practice what we have learnt in the course. My personal opinion is the course is as beneficial as the attitude and the participation of the attendees. Therefore the more involved one is, the more they will benefit from the course.

Thank you Lane Fox Unit for such an informative and useful course. Special thanks to the facilitators of the course Alexander Curtis (Physiotherapist) and Jeong Su Lee (Occupational Therapist).

Bosik Gharapetian

Trustee, The British Polio Fellowship



Trustee Bosik Gharapetian (second right) at St Thomas' with fellow Expert Panel members Jeong Su Lee (back right); Alexandra Curtis (back left); and other delegates.

The future of medical complexity: Understanding you and your care

Despite advances in medicine, it is often difficult for healthcare professionals to help patients within a ten minute appointment. I do not see patients as a set of problems but rather as individuals who have changing needs depending on their health and social needs. The needs of individuals with PPS are often complex, and this is an area of medicine many doctors are not overly familiar with; this adds to the difficulty of addressing the needs of those with these conditions.

In medical school, it is difficult, if not impossible to teach yourself and be taught everything in the world that could possibly go wrong with the body. In the Western world, acute Polio is not common and has been largely eradicated; because of this, many find that there are doctors and healthcare professionals who may not be familiar with PPS symptoms.

When the needs of patients are poorly understood or poorly known about, the impression this gives is one of unprofessionalism or lack of understanding.

I mostly stick to the ten minute timeframe, but this is difficult when some patients have either complex needs or they have a number of problems which may be unmanageable in the ten minute time frame. In ten minutes, it is expected that patients are sorted and on their way, though the GP still has to document the consultation and act on the plan.

My main role is as a Proactive Care GP in Brighton and Hove. This involves receiving referrals from GPs and other healthcare professionals regarding patients who may have complex health needs. These warrant an in depth whole person assessment which looks into what is important to them, what their medical issues are, what their social issues may be, examining them and finally arriving at a management plan.

Sometimes, if someone has many issues which warrant a wider professional discussion, I arrange a multidisciplinary team meeting (MDT) with other professionals. As you can imagine, this has many positives but also is not always fruitful due a number of factors.

Sometimes healthcare funding and availability of services prevent or delay appropriate care. Sometimes individuals

become frustrated with existing services and disengage through frustration, making collaborative working difficult.

In many areas of the UK, Proactive Care and Palliative Care teams exist to address the needs of patients with complex or chronic health conditions. Often patients are not familiar with these teams. Palliative Care is often associated with symptom relief for those towards the end of life, but in fact the speciality is involved in addressing the needs of those with long term conditions such as heart failure, chronic obstructive pulmonary disease (COPD), disabilities and also cancers. This is therefore similar to Proactive Care. Proactive Care sounds more positive though – right?

Why am I writing about this? Well, I have personal experience of my mother living with various medical conditions, including PPS. Doctors were not familiar with it and it was gutting to push for the care she deserved. Unfortunately, my mother lost her fight with illnesses and passed away two years ago. Although I strived to help her the best I could, I can now see that sometimes we strive to great lengths to help those who may have little chance of improvement or who may improve but do not have the knowledge of the appropriate services – or even access to them.

I am writing this article to highlight that if you feel that your health needs are not fully met, it might be worthwhile to discuss with your GP whether a referral to Proactive or Palliative Care is appropriate. This may be a phone call to your GP if there are no immediate medical needs.

Have a think about what I've written and consider whether you wish to have a greater part in your healthcare. Rather than seeing a doctor when things are not right, my opinion is to plan when you are relatively well and be proactive in getting your needs met. Be proactive rather than reactive. Be in charge.

Wishing you the best of health

Dr M Fabrowski

*nMRCGP (2016), MB ChB (Hons), MSc, BA (Hons)
GP (Sussex, UK) and Expert Panel Member (The British
Polio Fellowship).*

Information available from Support Services

In response to member feedback, we are no longer printing the traditional order form for the information leaflets and factsheets, as the majority of members now prefer to request such information and brochures over the phone and online. We want to reassure members that all information continues to be available from Central Office and all of them, (even the new Post Polio Syndrome: A practical guide) are now free of charge to members. A call to the Support Services will allow Ahmad Butt, Head of Support Services and his team to quickly assess your situation and recommend the most useful factsheets based on your unique needs. The Support Services team is led by Ahmad and his team comprising of Yvonne Wright, Aparna Tripathi and Sarah McHugh has a great deal of experience in setting members on the right path.

The full list of publications can be viewed on the new website at britishpolio.org.uk/services-information/resources-for-members/

Regards

Support Services Team



Useful Contacts:

Head of Support Services

Ahmad Butt 01923 281 093

ahmad@britishpolio.org.uk

Support Services Team

Disability Benefits, Information and Advice, all membership issues and enquiries

Yvonne Wright, Aparna Tripathi, Sarah McHugh

0800 043 1935

info@britishpolio.org.uk

PIP tips and advice for members

The British Polio Fellowship's Support Services team would like to remind members on the importance of Personal Independence Payments (PIP).

It is important to take your invitation for PIP seriously. You should call up the Department for Work and Pensions (DWP) as soon as possible when you receive the invite and make sure you return the completed application form before the due date. If you fail to do so, you may lose the benefit entirely and may have to claim Attendance Allowance if you are over 65. Attendance Allowance does not have a mobility component and most people are better off on PIP itself.

If you need help with filling the PIP form, you should get in touch with the Support Services team (above) at Central Office as soon as you receive your PIP application form. The team remains very busy

throughout the week and they will only be able to fit you in for an appointment if they have sufficient notice. Occasionally, the team may ask you to get an extension of deadline from DWP if they are unable to offer you an appointment before your due date.

It is also important to gather as much medical evidence about your history of medical condition(s) from the time you think of making the PIP application. You might want to arrange an appointment with your GP for a specialist referral or consultation for any new symptoms you may have noticed. Your application will only be strong with enough medical evidence that explains the full impact of your condition(s) on your daily life.

Please do contact the Support Services team on 0800 043 1935 if you would like to talk about PIP further. **b**

Positive PPS feedback from Somerset CCG

The Support Service team is pleased to report the following response from Somerset Clinical Commissioning Group to the Healthwatch Somerset and British Polio Fellowship's Post Polio Syndrome (PPS) in Somerset Report 2016.

Concerns over GP understanding of PPS

We recognise how important it is for people with PPS to receive sympathetic and well-informed care. Given the low incidence of Polio and PPS (120,000 estimated people who have survived Polio in the UK, of which between 15 and 80 per cent will be affected by PPS), it will be rare for GPs in Somerset to come across PPS.

We welcome the provision of a PPS information book for health professionals. However we think it would also be useful if this was available to people with PPS who could give it directly to their GP to inform the discussion of their healthcare treatment between doctor and patient. We could also promote the information booklet via our own engagement networks eg. via the PPG chairs network so that they can in turn help to raise awareness of PPS in their own practices, or via SEAG so that greater awareness can be cascaded to the wider community.

The CCG is participating in a national pilot which allows more time for GPs to respond to the needs and perspectives of individual patients rather than box ticking. We are also providing training and support for practices to deliver personalised care planning to people living with long term conditions.

Concerns over access to GP services

We know how important it is for people with complex and severe health problems to have continuity of care with key individuals. Through the Sustainability and Transformation Plan we are working to improve access both for people with an acute health problem that needs rapid resolution and also people who need to be able to see the same clinician on an ongoing basis. The multi-disciplinary approach to primary care may mean that the person is more likely to see the right professional

with the right expertise, rather than simply seeing their own GP who may not be able to offer a tailored or specialist service.

Concerns over access to orthotics services

An orthotics service is provided by all of our acute providers including Taunton and Somerset NHS Foundation Trust (T&S), Yeovil District Hospital NHS Foundation Trust (YDH), North Bristol NHS Trust (NBT) and Royal United Hospital NHS foundation Trust (RUH), Bath. NBT in particular has increased its provision in Somerset and now provides a weekly, all day clinic at Frome (on a Tuesday) and Wells (on a Wednesday). These replaced a once a month all day clinic at Wells and Frome and an alternate month clinic at Shepton. This was in an attempt to meet increased demand and reduce waiting times. These clinics are managed from the NBT base at Cribbs Causeway and booked there, and staffed by highly experienced orthotists. This has resulted in a significant reduction in waiting times already, and NBT expects this will continue.

Concerns over having to be re-referred by GP for orthotic maintenance

The positions of the different providers are set out below:

YDH - Patients can be referred by either a GP, consultant or Allied Health Professional and once known to the service can self-refer back into the service for ongoing care without needing another GP referral.

NBT - Patients will normally be referred by their GP or hospital consultant but thereafter may be able to self-refer depending on the nature of provision made. Typically, for patients with specialist footwear, for instance, they will be able to self-refer for review or repairs but if their clinical condition changes, or they require input for a different condition they will need to seek further information from their GP or consultant. Specifically, patients provided with devices will frequently be called back for review following their fitting appointment and then may be advised to self-refer if their



condition changes or if they have any particular concerns. With the increased demand on our services, and in keeping with general practice, we provide planned review for those who clinically require it. However, further reviews can be provided at the request of an existing patient directly, without the need for a GP referral.

RUH - Through the GP or consultant referred service. If there is not an ongoing need the team will discharge them, to manage patient flow and activity and a GP referral is required for follow up.

T&S - Patients may phone for a review when necessary. Time scale for review following the contact may be a few days up to six weeks depending on the reason for follow up.

Concerns over length of time to receive a service if patient has an issue with an orthotic

The time taken to re access the service will depend on the level of clinical need. This is assessed at the point of receipt of the referral. In the majority of cases this is between three days to six weeks. All providers try to see patients with urgent needs as quickly as possible.

Polio patients are an integral part of the client base for orthotics. The orthotists recognise the particular needs and do their best to provide individual solutions. Customer service is very important to the providers and they are disappointed that some service users have concerns

over the service that has not been highlighted previously through PALSS or the complaint systems.

We hope this response is helpful. We look forward to working with Healthwatch in future to improve the services available for people with PPS.

Best wishes

Michael Bainbridge

Head of Primary Care

*Somerset Clinical Commissioning Group
(Working Together to Improve Health and Wellbeing)*





Every issue we have a bunch of carnations, courtesy of Le Tourneurs, to send to the writer of one letter, so send your letter NOW!

Eric Cook

Dear bulletin,

Below is a small presentation I gave at the Manchester Polio Group meeting. I thought sharing it with readers of **the bulletin** would be interesting and helpful.

Other symptoms not related to PPS Ulcerative colitis

In February 2016 I started with the symptoms of what was later diagnosed as Ulcerative colitis (UC). I consequently spent three weeks in hospital on intravenous antibiotics and steroids. 12 months earlier I had gone through similar symptoms although not as severe as this time.

UC is a condition that causes inflammation and ulceration of the inner lining of the colon (the large bowel). In UC, tiny ulcers develop on the surface of the lining and these may bleed. It is a chronic condition; this means that it is ongoing and lifelong, although you may have periods of good health (remission), as well as times when symptoms are more active (relapses or flare-ups).

Although there has been a lot of research, we still don't really know what causes UC. However, advances have been made in recent years, particularly in genetics and we now believe that UC is caused by a combination of factors; the genes you're born with; an abnormal reaction of the digestive system to bacteria in the intestine; and an unknown 'trigger' that could include viruses, other bacteria, diet, stress, or something else in the environment.

It's estimated that UC affects about one in every 420 people in the UK (0.23 per cent). UC is also more common in white people of European descent, and it tends to develop more frequently in non-smokers and ex-smokers than in smokers – but health professionals strongly advise against smoking as a way of treating UC.

On both occasions I lived with UC I had just given up smoking so I was convinced that had been the cause and so started smoking again. It's nearly 12 months on now and I still smoke (10 a day) along with the subscribed medication and have had no flare-ups.

Breathing problems

On 21 April 2016 I saw my Gastroenterology doctor who in the note to my GP, said: "In clinic, Mr Cook was short of breath and this could be asthma. I would request if you could refer him to chest physicians on an urgent basis."

I was seen by a doctor who was a specialist in respiratory medicine who came up with some recommendations of which these were included: "Even though his chest X-ray is normal I will request a scan of his lungs to rule out any subtle diagnosis I may have missed out like scars on his lungs. I have requested him to push himself as far as his physical limits are concerned and gradually increase his exercise tolerance. I will refer him to the pulmonary rehab sessions at Failsworth PCC, provided he qualifies for such intervention in spite of his previous Polio."

I attended the rehab sessions for six weeks (twice a week), and have since been included in a gym course as a follow on to the rehab. This has resulted in me constantly oohing and arrhing when getting up or sitting down and having difficulty putting my coat on – so much so that my wife threatened me if I didn't tell the instructor that I was doing too much.

So I have problems with colitis, breathing and exercising.



What has this got to do with Polio?

Well when you consider that the Polio virus multiplies in the gastrointestinal tract before its journey to destroy the motor neuron cells, who is to say that it didn't have some effect on the gastrointestinal system?

The oral cavity, salivary glands, oesophagus, stomach, small intestine, large intestine, liver, gallbladder and pancreas all form part of the gastrointestinal tract. Now if these organs were affected by the initial Polio virus we can assume that PPS could also be affecting them today.

Last year the Fellowship issued the results of a survey they conducted on PPS. What were the main findings on how PPS had affected us?

Fatigue, muscle weakness, pain, cold intolerance, sleep problems and also respiratory problems and bowel and urinary problems.

Now take a look again at my recent problems. Nearly half of the people living with PPS had some sort of bowel or urinary problems and although the survey didn't state which type of problem, you can assume that UC would be one of them. Therefore my colitis could be down to PPS and the initial virus manifestation in the gut.

New problems with my breathing were put down to asthma or the deconditioning of my body due

to the colitis; however we see from the PPS survey that over 30 per cent of people living with PPS were experiencing respiratory problems, so maybe my breathing problems are side effects of my PPS.

I was told by my chest consultant to exercise and quote, "I have requested him to push himself as far as his physical limits are concerned and gradually increase his exercise tolerance."

By doing this I found I was getting more pains in my arms and lower back, and after reading about the type of exercise people living with PPS can do, I have had to change my exercise programme to compensate for this.

Therefore, I have come to the conclusion that these non PPS related symptoms could after all be attributed to the late effects of the Polio virus, because they have only started to bother me since I started to feel other symptoms that are attributed to PPS.

Eric Cook

Polio survivor attached to the Manchester Group

Ref source: Crohn's & Colitis UK. (2013). Ulcerative Colitis. Retrieved 4 April, 2017 from crohnsandcolitis.org.uk

Anne Martin



Dear bulletin,

I was interested to read the article in the last edition of **the bulletin** about travelling with PPS. I thought it would be useful for other members to read about my trip to the Caribbean and hear about my experiences of my cruise trip in March.

Train: Norwich to Liverpool St

The first leg of my journey began at Norwich train station. With me, I had my electric scooter and one large case. Norwich station staff are always extremely accommodating and you can in fact call up in advance to book assistance.

For example, you can be met at the entrance of the station, they can provide ramps on and off the train and can take your luggage for you. This service is free as long as you book it in advance.

There are only disabled spaces in the First Class carriage but you do not have to pay more to be seated here and you are therefore right next to the accessible toilet too. Unfortunately the toilet door stopped functioning half way through the journey but a female member of staff was very helpful and stood at the door to enable me to use the toilet.

My daughter met me at Liverpool St station and a booked car took myself and my daughter to Gatwick Premier Inn for the night.

Premier Inn Gatwick

The night's stay at Premier Inn was excellent. All of Premier Inn's bedrooms have been designed for use by disabled people and the most accessible bedrooms are usually located close to reception or a lift lobby.

The bedrooms are designed to allow wheelchair users adequate space to travel around the room and manoeuvre their wheelchair. The entrance doors to accessible bedrooms are fitted with wide angle door viewers (spy holes) at both seated and standing levels.

All accessible bedrooms are provided with emergency assistance alarms. Each of the accessible bedrooms also have en-suite bathrooms with wide entry doors for ease of access.

The bathroom was fitted with a shallow bath, with the bath rim at the same height as the majority of wheelchair seats (480mm), and grab rails around the bath. These aid transfer from a wheelchair to the bath.

All Premier Inn Team Members receive disability awareness training which showed in the very warm reception we received.

Gatwick Airport

You should always book assistance in advance with your airline or your travel agent, if you need help at the airport. This is so that they can have the right help and equipment ready for you at the airport.

From arrival the team at the airport was very helpful. Under European legislation, your airline is responsible for providing assistance when you are on board the aircraft and will help you while you are at the airport.

The Gatwick staff were informative and gave me advice on where to go at what times and helped with the transport of my electric scooter. The escort took me and my scooter to the door of the plane. My escort then asked if I needed assistance to my seat on the plane but this was not necessary as I can walk short distances.

I booked a seat near the toilets and was able to use the toilets in the upgraded section of the plane so that I did not have to wait in a queue.

Barbados

On arrival at Barbados there was a team ready and waiting with an Ambilift for my scooter. When booking your cruise, you need to tell P&O if you have a disability which means that they can provide additional assistance.

P&O had arranged a car to take us directly to the ship too. Their disability team collate this information and ensure that each ship has a list of guests requiring extra assistance, together with their cabin numbers, before the ship sails.

Mobility scooters are only permitted on board if guests have booked into a wheelchair accessible cabin, or selected Suite/Mini suite so make sure to do this. It is to ensure there is sufficient space for the scooter to be stored safely.

Cruise ship – Britannia

I was excited to go on the Britannia, which was voted the Best New Ocean Ship at the Cruise International Awards in 2015.

I was allocated an adapted room as per my booking. The room had plenty of hand rails in the correct position and a balcony big enough for a wheelchair i.e. a ramp dropped down as the sliding doors opened.

The bathroom was a wet room style shower room, with a flush threshold into the cabin and grab rails for shower and toilet, as well as a pull down shower seat.

Around the ship there were plenty of disabled access toilets however, some of the doors were too heavy to open but staff were able to help me. There are allocated wheelchair spaces in the theatres and other entertainment venues for the use of full time wheelchair users and their companions.

As a safeguard, I had booked a wheelchair from Mobility at Sea as the received wisdom seems to be that Caribbean transport is problematic. Mobility at Sea offer a wide range of products and will recommend and allocate a wheelchair once they have conducted a brief verbal assessment ensuring that you hire the most suitable option.

Caribbean Islands

Staff were able to provide wheelchair and arm assistance from the top to the bottom of the gangway for going ashore. In Dominica I booked a coach trip around the island and my wheelchair was accommodated too.

Dominica is a beautiful island, which has remained very unspoilt and culturally preserved. Known as "The Nature Island," Dominica's tropical rainforests cover two thirds of the island, and are home to 1,200 plant species.

Another day I visited Tortola and left my wheelchair safely at the coach park. I once again took a coach trip around and the also hired a car to a quiet beach. The powdery white-sand beaches, lush green mountains, and sheltered, yacht-filled harbours were stunning.

The final noteworthy excursion was to St Martin. I booked my wheelchair in advance with the coach company so this was no bother. Unfortunately, the streets in the French quarter were not suitable for either a wheelchair or a scooter.

St Martin offers much more than just stunning beaches; it is teeming with natural, cultural and human riches. If you like shopping then St Martin might be for you as although many other tourist destinations claim to be duty-free, St. Martin is the only destination in the French West Indies that can truly lay claim to a tax-free status. With no customs duties, VAT or other indirect taxes to pay, the island offers unbeatable prices on a whole host of items.

Anne Martin

Norwich

Gill Thompson

Dear bulletin,

I am writing in response to the Travelling with PPS article in the last issue of **the bulletin** (Spring 2017). I had major problems with the article because I think it makes life more complicated than it needs to be when travelling abroad.

I developed Polio in Libya when I was four and my dad was in the army. I ended up wearing a calliper on both legs and a few years ago had to start using a wheelchair – but neither of these facts have ever stopped me travelling round the world both for pleasure and work.

In addition to Libya, I have visited USA, Kenya, India, Dubai and most of Europe. I have never had a letter from my GP and have never had a problem with customs. I take 10 different oral medications plus insulin for type 2 diabetes and also have to have a blood sugar monitor with me at all times. I always take my prescription with me in my hand luggage but only take the actual amount of medication I need.

The idea of taking it all in the original and correctly labelled packages would take up too much room in the hand luggage, and the idea of taking a spare supply in my suitcase as well is again for me just not a good idea because of the room it takes up. In any case I would not have enough original packages. I only have one month's supply of medication at a time for each medication, so if I have the medication I need in its original packaging in my hand luggage, I would not have any medication in its original packaging to put in my suitcase. I have only once in all my travels lost any part of my hand luggage and that was last year in Italy and the only thing that went missing was my medication; because I still had my prescription, I was able to get it all replaced at the local pharmacy.

The problem with getting a letter from your GP is that you would need a new one each time you travel, especially if you have to include your itinerary each time. As these letters for some GP practices can cost £50 or more, it can be expensive if you go on more than one foreign holiday per year.

I believe I have PPS but both neurologists I have seen believed there is no such thing - it is just aging with a disability and therefore I cannot include it when buying travel insurance. I do have 14 other long term health

conditions though (including Polio) all of which of course I declare in advance.

I do believe the Travelling with PPS article from the last **bulletin** (Spring 2017) has given readers the impression that travelling with long term health conditions is fraught with difficulty, but it is not.

I have travelled abroad for 65 years, both with and without companions, as a single person and as a married person; and I can honestly say I have never had any problems with taking just the medication I need (without the original packaging) – as long as I take my prescription as well (except for last year when my medication was stolen from my hand luggage).

Only twice have I needed a letter regarding medication; the first was when I went to Cyprus four weeks after a cataract operation, and the second time was when I had just developed type 2 diabetes and was prescribed insulin. Both times I was given a letter from the hospital and did not have to pay.

Gill Thompson



the bulletin deadlines and postal dates 2017

As part of our improved production and printing efficiencies from the start of this year, we are now able to tell you when **the bulletin** should be posted/available on the website.

We're sure you'll agree it is a major step forward to be able to predict roughly when **the bulletin** will be posted, and therefore received. This process has taken a long time to refine and has been brought in to respond to members' requests for better visibility on when **the bulletin** is being produced and posted. The impact of this new level of precision on the distribution date, however, is that there is now little or no flexibility on copy

deadline dates. Hence, if you want to have your material considered for the Autumn edition being posted on 1 September, for example, you must have your material with us by 21 July. After that date, we cannot guarantee that there will be time or space to include it.

Please remember also that **the bulletin** will take a few days to be received from the postal date as it is sent 2nd class to keep down escalating postal costs. Therefore, if you have events and diary dates that you want promoting in **the bulletin**, be aware that anything dated 8 September or earlier (for the Autumn edition, for example) will already be out of date by the time **the bulletin** is received by members. Whilst this may sound obvious, we do receive a fair number of submissions that cannot be used, because the dates being promoted would be historic by the time **the bulletin** is produced, printed and distributed.

If you have events and diary dates that need promoting before 8 November, they need to be in the Autumn issue, deadline 21 July.

The copy deadlines and postal dates for the remainder of the year are below:

bulletin deadlines for 2017

Issue	Copy deadline	Posted by
Autumn	21 July	1 September
Winter	22 September	1 November
New Year	17 November	27 December

Classified For sale



E-Fix Alber Action 3 Electric Wheelchair.

Black and grey, purchased in 2009. Has a rechargeable battery, easily dismantled and can be converted into a manual wheelchair.

Cost £4,406 but will accept £500.

Contact 01524 67581.

Lancaster area.

Colin Crook

Dear bulletin,

Below is a short story of Dorothy Crook's life, as written by her husband Colin.



Dorothy Crook

I was born in November 1934 and for five years was a healthy young girl until I caught Polio. I was admitted to Ottershaw Hospital where I was put in an iron lung for six months.

I can remember in 1940 when the area

was being bombed, and the nurses had to pump the ventilators by hand. I slowly progressed and left hospital with a back brace, two callipers and crutches.

I was able to go to a normal school and after managed to get a job. In 1955, I got married for the first time, and moved around RAF bases including going to Germany.

We returned to the UK in 1956 with three children; it was then that I decided to divorce my husband.

In 1968 I met Colin. We were close friends for six years. We married in 1975 and moved to our own house in Sutton St. Nicholas in Hereford, where life got very busy.

Colin and I started our own market stall selling sweets and babywear. We moved around the country with the stall and then set up a 20 stall market in Strand,

Gloucestershire, which I ran as Colin was still an electrical engineer with the Midlands Electricity Board (MEB).

In 1985, Colin resigned and we went full time on the market, which was great fun. Whilst all this was going, I was very active in The British Polio Fellowship.

One of the great memories was going to the get together of the branches at Daughtry in Worcester, where a lot of good shows were put on and games enjoyed.

Colin retired and I volunteered more. I was elected to be a Trustee in the services for Independent Living; a Trustee for The British Polio Fellowship; and a volunteer for the Pain Management in Brecon.

It was interesting and enjoyable. I gained a lot of knowledge and information to enable me to support other people in pain. I met some really nice people and made a lot of very good friends.

Sadly, pain and suffering got the better of Dorothy and she passed away in Bromyard Community Hospital near Hereford on 17 January 2017, after 82 years of a very interesting life.

Colin Crook

Diana Marshall

Dear bulletin,

Perhaps it would be of interest to readers to know that two books about people who had Polio have recently been published – The Next Bend in the Road and Saldo Cay.

The first book, written by myself, takes the reader on a journey with twists and turns along the path of my life.

I have lived with a permanent disability, which came as a result of contracting Polio at a young age, and as a result a full time wheelchair user as well.

I have lived in two countries with a very different attitude towards disability, and travel extensively. In my book, I

reflect on these and other topics, such as relationships, opportunities in life, and of course I couldn't leave out Polio because it has shaped the course of my outlook on life.

My husband meanwhile thinks that there aren't enough books with Polio survivors as the main character, so he wrote Saldo Cay, a novel featuring a female wheelchair user in the leading role – Nancy, who had Polio as a child.

Both books are available for sale in bookshops worldwide, and on Amazon (paperback and eBook).

Thank you

Diana Marshall

Erik Cramb

Dear bulletin,

The following article concerns issues raised at a recent meeting of the British Parking Association in Dundee. Although, as you will see, it was specifically about Scotland, there were representatives of parking authorities across England also present. Thus, there can be little doubt that the questions about paying for parking will be raised by authorities throughout the UK. Many Polio members will be dependent on their blue badges and would wish to be alert to any threatened changes.

The Scottish Government is currently carrying out a review of the effectiveness of the Blue Badge scheme. At the spring meeting of the British Parking Association Scotland, there was a discussion about the current scheme and if it's indeed the best way forward for Scotland.

Although this is a devolved matter, you can be sure that the answers to the questions being raised will be studied carefully by authorities elsewhere in the United Kingdom. Amongst the issues raised were the following:

- **Should blue badges continue to have free parking?**
- **Should it continue to be without time limit?**
- **Does the scheme deliver the benefits users expect?**
- **Is fraud still prevalent?**

I was invited to take part in the debate. In my address to the meeting, I began by saying that few would dispute the fact that the effects of the UK Government's austerity policies have hit the most vulnerable in our society hardest. I also said that people with disabilities were generally amongst the most vulnerable and that any suggestion that persons with severe mobility problems should have to pay for parking was a mean and miserable suggestion.

It would raise a miniscule amount of revenue in government terms but hit individuals hard. Blue badges, like free bus passes, Rev Cramb concluded, are keys of liberation for holders and therefore free parking should be vigorously defended.

The time limit question is specifically Scottish because unlike in the rest of the UK there is no time limit here on Blue Badge parking.

There are many instances in Scotland's major cities of cars with blue badges being parked all day in the city centres. This doesn't help the flow of traffic argue some parking association members, and they also say it's not good for city centre shopping trade.

I resisted this argument, pointing out that this parking without time limit allowed some people with mobility problems to access employment in town which otherwise they could not. I pointed out that unemployment amongst people with disabilities runs at something like seven times the national average.

It is generally accepted that the ability to get out and about and participate in normal life is highly beneficial to the health of people with disabilities and that any savings made by limiting the Blue Badge scheme would end up adding to the costs of the NHS.

On the delivery of the expected benefits of the scheme it seems that in terms of parking in public places, yes it does deliver, but in private car parks, particularly those of the big supermarkets, it is not working.

When the discussion turned to fraud there were frightening statistics produced by a campaign in Glasgow which indicated a horribly high incidence of fraudulent use – usually by family members. I said that I had no doubt that all genuine Blue Badge holders would strongly support a clamp down on this.

Members of the parking association then talked about the difficulties of enforcement and how it appears that in the immediate future the numbers of parking attendants would be very unlikely to increase and that in fact with the pressures on local government budgets it was far more likely that they would be reduced even further. There seemed to be a sensible argument for an increase in the fine for parking in a disabled space without a Blue Badge to at least £100.

Our Blue Badges are little treasures and we must be vigilant in protecting and defending them. It was heartening to know that this is well understood by the British Parking Association.

Erik Cramb

Notts and Derby Branch

Over 40 members gathered at Eden House Hotel in Grantham from all areas of the East Midlands region for lunch. A lovely lunch was enjoyed by everyone. Here are a few photos taken by a Notts and Derby Branch supporter, Martin.

Barbara Worrall

Chair, Notts and Derby Branch



South London Branch

We are a small, friendly group and meet regularly at Newlands Hall, Roehampton, London, SW15 3EP.

Our next discussion meeting is on 3 June. On 1 July, we will meet at the Wetlands (WWT) Centre in Barnes, SW13 9WT at 3.30pm and have tea together. For further information, please phone 020 8785 9647.

Sandy Walline

Leader, South London Group

Leicester Branch

First of all, I'm sure you all enjoyed the Christmas meal at the Marriott Hotel as I did. They are always very good; the staff are always ready to help in any way they can.

Prior to Christmas, we had a good trip out to Wicksteed Park on 24 November, with a nice meal and show. Thanks to Genny.

In total, 22 members of the Leicester Branch and 14 members from Northampton Branch had a very enjoyable afternoon. The lunch was traditional Christmas Fayre and the show was called Oh What A Christmas Cracker.

It was all very enjoyable and a nice way to come together and celebrate the festive season. During the show, afternoon tea was served and the bar was open for those who wished to partake in something stronger.

Sandra Clegg

Forthcoming social events

8 June – Cricket match at The Mosaic.

This event was reintroduced by Harry Parkin last year and proved very popular.

14 June – Kilworth House Theatre: 'Kiss Me Kate'.

22 June – Book now for the visit to Bosworth Battlefield Visitor Centre and a meal.

23 August – Kilworth House Theatre: 'Top Hat'.

Apart from these dates, normal meeting dates are on the second and fourth Thursdays each month.



Marlene Hollis

Note from the Chair

Our many thanks are due to Marion Whitby, of the Nottingham & Derby Branch, for organising the regional meal at the Edenhall Hotel, Grantham on 6 March. This event was enjoyed by all who attended. Thanks also go to Mary Smith for providing ramps to help wheelchair users to get up the few steps.

Unfortunately, two members have resigned from this year's committee. We thank them for all their hard work in the past. This leaves two vacancies on the committee to be filled.

Social

At the meeting on 23 February, Mike Jackson of the Northampton Branch gave a most informative talk on the benefits of the Chris Moody Hydrotherapy Centre at Northampton.

Following the recent National Indoor Games at the Leicester Marriott Hotel, our sincerest and grateful thanks go to Sandra Clegg and Mike Poole for their sterling work towards the organisation of the successful event.

General

We hear congratulations are due to Margaret Abbott, who has been elected President of the Ladies' Section of the Syston Bowling Club. Well deserved, Margaret.

Holidays

Mary Smith has passed on some information to us about a Disabled Adventure Club Holiday in Peebles, Scotland, commencing 23 July for seven days. The cost is £575 for half-board, staying at the Peebles Hydro and includes coach travel from Leicester and Loughborough but does not include insurance. There is a single room supplement. Contact Mary for more details on 0116 230 3325.

Welfare

We wish Sharda a speedy recovery from her accident, in which she sustained a broken leg. Our good wishes go also Susan, who has sustained two falls recently. Unfortunately, none of us bounce back like we did in the past. Get well soon to all of you who are struggling with health just now. **b**

South East Kent Branch

Greetings to all Fellowship friends; I am writing this on a sunny day in early March looking forward to springtime heralded by some lovely crocuses in my garden.



Our branch is now in the happy position of having been given two substantial grants for modern, lightweight folding electric wheelchairs.

One is destined for our member Shirley, pictured below with Viv during a branch lunch in an Edwardian seaside restaurant. Shirley's husband Mike, has had two strokes so this will be so much easier for them both.

The other will act as a branch wheelchair and be used for day trips, post-op help and other reasons.

The branch has welcomed several new members in the last three months, some of whom have already been to our monthly lunches. Others meanwhile will be joining us when meeting nearer to their homes.

Like other branches, the last year has seen various traumas amongst our members; bereavement, joint replacements, falls, heart scares and surgery. I feel justified in saying that I am proud of each and every one of our members for always coming through with a smile.

Kevin relaxes in the new branch wheelchair at Thanet Indoor Bowls club.



Quite a few are also undergoing the Personal Independence Payment (PIP) assessments which of course, are quite stressful; but always be assured that Central Office can offer additional help with advice and support during the ordeal.

We are a friendly mob who support each other through thick and thin. If you would like to join us, come and meet us all.

Here is a list of our upcoming monthly lunch venues, usually the fourth Thursday every month. All are welcome and you don't have to be a member of our branch to come along.

29 June - The Cider Works, Sandwich Road, Waldershare, CT15 5AU.

27 July - Farthingloe, Dover.

24 August - Quex Park, Quex View Road, Birchington, CT7 0BH.

One of our planned day trips is on 15 July, where we will be meeting for lunch at The Chef and Brewer, Wateringbury, ME18 5NS at midday prior to a now fully booked cruise on the Medway. Feel free to come along to the lunch and then wave goodbye from the jetty.

Email Angela on: flamingo@btinternet.com or ring the Fellowship on 0800 043 1935 for further contact details.

Readers may also be interested in the following email received from Transport for London:

I'm happy to confirm that Blue Badge holders will be eligible for a 100 per cent discount on the T-Charge which starts on 23 October 2017.

However, on page 10 of the consultation and information document, found through our website, I found that Blue Badge holders will not be eligible for a discounted ULEZ charge. **b**

A Couling

Shirley and Viv during the branch lunch.



Worthing and Sussex Branch

To celebrate the end of a very successful year for the branch in 2016, we held the AGM in the Durrington Community Centre in April 2017.

We remembered seven get-togethers with speakers; three summer outings; two pub lunches; 10 committee meetings; 30 craft club meetings; one craft club lunch; seven flag days; and one annual branch lunch. Oh, and of course, a branch holiday to Ross-on-Wye.

Yes, another very busy year and financially a most unusual one; we actually made a surplus (profit) of £539 on an income of £16,238, with therefore expenditure of £15,699.

Our income was boosted by a most generous donation of £3,000; sadly, major donations in memory of two deceased members, and of course £1,500 net profit on our Christmas draw and receipts of seven flag days.

Included in our expenditure was a net figure of £2,994 for all our events, transport for disabled members at £1,346, room hire at £1,067; and admin of only £175. We were also very pleased to be able to make numerous welfare grants, totalling £5,471.

The meeting re-elected our eleven committee members with grateful thanks for all the time and effort they put in.

In AOB, some forceful discussion criticised the recent survey in **the bulletin** with opinions being asked of members without any background costs explained.

One question in particular that was widely criticised was regarding the possible sale of the Burnham Bungalow, which actually makes a profit for The Fellowship.

The question was also asked is it possible that the sale of the Burnham Bungalow is really to help pay for the new Central Office?

The meeting closed with the delivery of fish and chips for our 40 members.

The branch is now looking forward to another busy year with outings to the huge British Airways i360 in Brighton, the House of Commons in London and a trip to a new Heritage Centre and lunch at a super garden centre in mid-Sussex.

But don't the years pass so quickly!

Bob Stephens

The Committee, Web Manager, President & Vice Presidents



Top Row: Secretary, Janet Jones; Birthdays, Carole Cressdee; Raffles, Terry Studd; Welfare, Outings, Gill White; Treasurer, Roger Jones.

Middle Row: Web Manager, Robin Stephens; President, Clare Colfer; Chairman, Bob Stephens; Newsletter, Craft Club, Barbara Stephens.

Bottom Row: (Bring & Buy), Carole Wyeth; Vice President (one), Ann Packham; Vice President (two), Beulah Nicholls; Raffles, Roger Brand.

Northamptonshire Branch

Branch hydrotherapy programme

On 7 April, the initial hydrotherapy programme was completed and a full report on it is available to other branches of The British Polio Fellowship on request.

Feedback from those members participating in the initial programme was very positive and as a result, a further six week programme commenced on 21 April. Following the success of the initial programme, two more members joined the second programme.

The Wellingborough Hatton Branch of Rotary International attended one of the sessions to observe members taking part in the programme. They have advised us that they will support a further programme.

Fundraising for our current hydrotherapy programme.

Rob McGoldrick, the husband of a branch Polio survivor, took part in a sponsored fund raising run at Irchester Country Park on Sunday 23 April.

Over 250 people took part in the race, and Rob was amongst the early competitors to finish. At the time of writing, Rob's run raised over £500, which covered the cost of our weekly group attendance at the hydrotherapy pool up until the end of May.

To support the continuation of the hydrotherapy programme, funding applications are being progressed by the treasurer to both the local council and other Northamptonshire organisations.



Rob McGoldrick with his medal after finishing the sponsored fund raising run at Irchester Country Park.

Orthotics

As a result of Northamptonshire Branch members experiencing problems with the orthotics being supplied by a national company, and following discussions with members of the Leicestershire Branch, it became apparent that a number of members were reluctant to complain about faulty equipment. Their reason for this was that they were concerned they would lose the support of the orthotics supplier in question.

This was reported to the orthotics company, and one of their managers investigated cases of faulty equipment in both branches. Following this, the manager has agreed for modifications to be made in one instance, and in another for a new replacement KAFO to be supplied. We would be interested to hear if other branches are experiencing problems with orthotics.

Branch support from the Wellingborough Hatton Branch of Rotary International

Rotary invited the branch to have an information stand at its Regional Rotary International Open meeting at Overstone Golf Club on Thursday 9 March.

Supported by the publicity material provided by The British Polio Fellowship's marketing department, we were able to promote the services and information available to Polio survivors, both at branch and national level.



Left to right: Rob McGoldrick with Northamptonshire Branch Chairman, Peter Mains.

Northamptonshire Branch



Back row, left to right: Bob Osbourne; Peter Mains; Rhiannon Hodges (Physio); Alan Waller (President of Wellingborough Hatton Branch of Rotary International); Kirsten Good (Physio Programme Instructor) and Dick Parsley (Rotary). **Front row, left to right:** Branch members Virginia Olds; Linda McGoldrick; Bryan Chettle; and Seth Thuita.

Over 100 Rotary branch members from Lincoln in the east and St Ives in the west attended the evening. During the evening, a number of new contacts were made with Rotary branches in Northamptonshire – this will be followed up on in the coming months.

Monthly branch meetings are on Tuesdays at 2.00pm, and held in the community room at Tesco, Victoria Park, Tunnells Mill Lane, Wellingborough, NN8 2EF.

Dates for next meetings

Tuesday 27 June, 2.00pm

Tuesday 25 July, 2.00pm

Mike Jackson



Left to right: Carl Weininger; Peter Mains, Alan Waller (President of Wellingborough Hatton Branch of Rotary International); Nigel Grimmit (President Elect of Wellingborough Hatton Branch of Rotary International); and Mike Jackson.

King's Lynn Branch



Left to right: Mick; Peter (the driver); Sam; Robin Sr; Reggie; Alan Hall; Dave is behind the camera, (Alan Bate and Robyn Jr are absent).

Day at the motor racing

King's Lynn Group member, Robin Hood, invited members to join his team for a Paddock Day at the Snetterton Circuit.

Alan Bate, Reggie Gray and myself accepted the invitation and went on 1 April (this is a real story!).

Robin's team – Robyn Jr; Sam; Dave; Mick; and driver Peter – had set up the catering-come-workshop camper, car transporter and covered working area. We were immediately introduced and welcomed with teas and coffees.

Considering the teams were amateur there was an atmosphere of professionalism as all the teams practiced and prepared their cars, which ranged from lightweight Lotus and Cavendish 7s (open single seaters), to Morgans, Minis, Triumphs and a whole assortment of sports and saloon cars.

Robin has an ex-works Porsche!

During practice and qualifying, Peter managed to achieve fifth overall and first in class. That done, we set about the highlight of the day – lunch! The Champagne and caviar was absent but the spread was fit for a king – and more tea.

Over lunch, Peter and the tech boys analysed the computer data to find chances for tuning the car or for Peter to find driving improvements – braking points, racing lines etc. The car received a full service.

Leaving the team to their work, us lay people went trackside to enjoy the races. The day stayed dry and we enjoyed the excitement, noise and smell of live motor racing.

Robin's race was the climax of the day with the top cars and teams competing. Peter brought the Porsche home in fourth place (first in class), a worthy result for the team and a real buzz for us visitors.

A great day out and many thanks to Team Arrowpak.

(For the observant I spied a calliper hinge (below) that had been commandeered in the gear change mechanism. We needed a Polio slant to this story – what other uses can redundant/broken callipers be put to?)

Alan Hall



The caliper hinge mentioned above.

Merseyside Branch

Thanks to member Gill Griffiths for organising a narrow boat trip along the Leeds to Liverpool canal. The Pride of Sefton 2 is 60 foot long, 12 foot wide and fully accessible for disabled people. The crew couldn't have been more helpful and good humoured.

The boat has a great history with a number of illustrious passengers in the past including the Windsor family. A good time was had by the members.

Linda Davenport Morton and Beryl Brereton presented Hilary Davies with flowers on behalf of the branch for her loyal service as secretary for the last 16 years. Thanks to Hilary for all her hard work.

We'd like to thank Mr and Mrs P Richards for donating their wedding gifts to the branch funds; thanks for your kindness!

We would also like to express our sincere thanks to Mrs Gill Morrow and friends for the generous donation they gave to the branch. We were overwhelmed by the amount they raised through what appeared to be a very gruelling challenge. [b](#)



North London Branch

Our new President, Jennifer Wootten's speech, at our AGM on 11 March 2017:

One day the committee said to me,

Would you stand for the Presidency?

I'm flattered and honoured I think is what I said,

(While inwardly I really was filled with lots of dread)

I'd have to follow Edith, not an easy thing to do,

And welcome all the speakers, and talk at this meeting too,

I must first thank the committee, I'm sure you want me to,

For arranging all the meetings, and the other things they do so well,

Especially Janet and Teresa who have had to cope with illness and yet make all things gel,

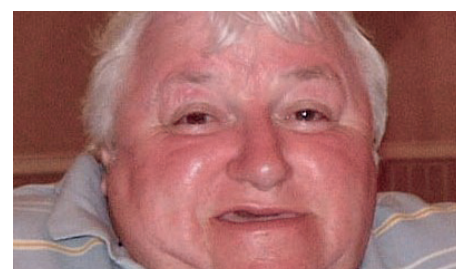
I must not forget the others, who each help in various ways,

All the washer-uppers, raffle runners, prize donators, chair and table movers who make things much easier on meeting days,

People wise, I have to say, what a sad year it has been,

We've lost Edith, David Leeder and dear Jimmy McKean,

Let's hope this New Year brings us enjoyment and much pleasure.



After Christmas we received the sad news that our Treasurer, Jim McKean died suddenly; he'll be sorely missed. We are grateful to Charles Raymond who acted as our Interim Treasurer until Jenny's appointment. Gaye Lockyer has agreed to become our next Regional Representative. Forthcoming events and dates for your diary

10 June – Professional entertainer (still to be arranged).

Janet Drinkwater, Social Secretary

Lincolnshire Branch

Like most charities, the Fellowship finds it difficult to raise funds; because of our advancing years, mobility problems and British weather, outside collections are not ideal for us.

However, the Lincolnshire Branch has raised £440 with just two main collectors (Branch/National Chairman, David Mitchell, and myself) at our two main Tesco stores in Lincoln. We were given a table, some chairs, and a room to put up Fellowship publicity - always available from Central Office.

Prior arrangements are essential through the company's charities co-ordinators charitycollections@tasteattesco.co.uk and booking can be done online.

Staff were very helpful and gave us free, very welcome, hot drinks on two cold days.

£440 is a welcome addition to our branch funds and means we can help members in many ways.

A good return and we recommend this type of collection to you all.

Caroline Gordon-Wilson

Secretary, Lincolnshire Branch and East Midlands Region

PS: Special thanks to Philip Payne, a good friend, who on arrival from London stepped in to allow us a comfort break and proved to be a natural, charming charity collector.

STOP PRESS

Central Office staff, the Trustees and **the bulletin** team would like to offer their congratulations to The British Polio Fellowship CEO, Ted Hill on the birth of his first grandchild, Oliver Edward. Mum and baby are both doing well.

STOP STOP PRESS!

The Hill family have been busy and we are delighted to report the arrival of Ted's second grandchild, Tilly Louis into the world, just a few days after Oliver. **b**

Yorkshire Region

The AGM will take place on Sunday 4 June 2017 at the Ferrybridge Community Centre, The Square, Knottingley WF11 8PR, at 2.45pm.

Joanna Watson, *Hon Secretary Yorkshire Region - SPPN Chairperson*

Scottish Polio Network

Newsflash from Scottish Post Polio Network

We've been working with the Scottish Government and managed to set up a dedicated link to Patient Opinion Scotland as detailed below.

It would be helpful if any Polio survivors could use the below link to let us know their experiences when seeing GPs for PPS.

We continue to work with Patient Opinion, a not for profit social enterprise. They use the web to carry the voices of patients into the heart of the health service. Scottish health boards and Members of Scottish Parliament (MSPs) have welcomed the opportunity.

Patient Opinion has agreed to set up a new Post Polio Campaign code. We are now asking all members to use

this link to put forward their experiences, whether they are positive or negative. This is an anonymous service, only giving emails for follow up by Patient Opinion.

People who don't have a computer or internet access will be given the option to write their story and we will send this onto Patient Opinion for inclusion on the site.

www.patientopinion.org.uk/youropinion?cc=sppn

Things to include are summary of direct personal experience of health and care; the impact it's having on you; how you're feeling and what you would like to see change.

Helene MacLean

SPPN Chairperson

THE CORDWAINER

Does your footwear reflect your lifestyle?

Does your independence and pride have to take a back seat when it comes to footwear? Is there someone you can go to who understands that the quality, comfort and appearance of your footwear is important?



I am Philip Taylor

- I live with the effects of Polio.
- 30 years in the trade.
- Member of The British Polio Fellowship's Specialist Orthotics Panel.
- I specialise in taking on the most difficult footwear for disabled people.
- Limited home visiting service.

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* Applies to all orders 1 month from magazine print date.

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www.thecordwainer.co.uk

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History Corner

More on The Lantern Hotel - and beyond

I'd like to apologise for the brevity of the article this time round. As you will have read in the Travels with My Wheelchair article in this copy of **the bulletin**, I have recently moved house and have yet to track down the box containing my past issues of **the bulletin** for source material. This will be remedied before the next issue falls due – fingers crossed.

In the meantime I'd like to thank Christine Peverill for getting in touch after the last feature on the opening of The Lantern Hotel in Worthing. She was one of many who enjoyed a holiday at the hotel, but tells of being invited to attend a wedding, by a member of staff, of two Polio survivors during her time there. Not only was this unexpected, and certainly not the reason for her stay at the hotel, but for whatever reason, the wedding itself was filmed by British Pathe, and no doubt shown in cinemas as part of a Pathe News feature between film presentations.

I mention the Pathe news because Christine also told me that the film could be found on YouTube. Well, of course, I had to have a look didn't I? If you'd like to view the film as well – there's no sound unfortunately – then you need to enter the search term “invalids wedding” into the search box on YouTube and there you have a wedding from 1954 – so Christine tells me.

Needless to say, my interest was now piqued. Was this the only Pathe film on YouTube featuring Polio survivors? A further search brought up a number of films, mainly featuring early trike rallies. I was delighted to discover these early films showing so many adventurous disabled motorists, but I have to say that I am glad that today we have more substantial vehicles to travel in. Many of these early trikes look to be open to the elements – not to mention being rather low to the ground I was reminded of the Sinclair C5 while watching some of the films. These trikes are remarkably easy to move when they become stuck in the mud, or go off road – a couple of strong fellas seem to be able to lift the trikes and they are off again.

While exchanging emails with Christine, I was interested to discover that there is a Facebook page for Polio History. Unfortunately I was unable to access much as this is a closed group and the only admin for the page was Barry North. It does seem a pity that the page has been left to languish since Barry passed away. I shall be looking into what, if anything, can be done to resurrect it. If anything can be done, I'll report it here, so look out for further news.

Following the passing of Anne Rowley, as well as Bryan, I have been entrusted with Bryan's personal archive. I am immensely honoured to be given access to these papers, given the role that both Bryan and his father played within the Fellowship. Once I am properly settled into my new home, I hope to spend time going through these papers and finding something to share with you all.

In the meantime, the photograph here shows Mr and Mrs Bradford on holiday at The Lantern Hotel, together with some other holiday guests. It must have been a warm summer – look at how wide the windows have been opened!

If you have memories to share, they can be sent to Bulletinhistory@outlook.com, or to Georgina Hay, 31 Ayr Road, Cumnock, KA18 1DZ. **b**



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Did you know that you can make a donation to The British Polio Fellowship just by going on holiday?

The British Polio Fellowship has partnered with probably the UK's fastest growing travel company, Not Just Travel - every time you book a holiday with Not Just Travel, they donate to The British Polio Fellowship. The British Polio Fellowship now have their own dedicated travel website which gives members a special 'concierge style' service from a highly trained Travel Consultant who will look after all your travel needs.

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My Way



I contracted Polio in 1955 just before immunisation was available in the North West. I was treated in Fazakerley Fever hospital as it was then called (now Aintree Hospital, Liverpool) and remained there for nearly two years.

I was unconscious for three months and my mum was told I would not survive. My breathing was done for me during this time by mechanical means.

I had 10 years of physiotherapy in the pool, and twice a week an ambulance would call at my school and return me there after my physiotherapy. During these years I had my neck support removed, which in those days was made from another patient's newspaper (The Times, I think).

I had a frame on my right arm, a support sling on my left arm, a half calliper on my right leg and a full calliper on my left. All these items were slowly not needed thanks now in retrospect to a ruthless physiotherapist called Miss Allen. She made me walk the iron parallel bars until I cried. Together with several operations for leg lengthening's and muscle transplants, I was able to have a relatively normal life.

I stayed on at school to catch up with my education, then went to college to do a Laboratory Technicians

course. Working in research for a short while, I then went to work in a school laboratory where besides having eight years off to bring up two children, I am still working for 40 years in total.

For the last 26 years I have been at Maghull High School where a very understanding staff and environment has helped me to keep working in a job I thoroughly enjoy. I think I have been able to contribute positively to many thousands of children's education and been a support to hundreds of teachers.

My husband of 43 years has been my true aide over the years; he has supported me doing all the domestic work I could not manage without any complaint, and when I have had accidents – I have broken seven bones with falls – he has looked after me as well as our children.

I am very proud of my own children; two daughters, one who's become a Senior Specialist Registrar Paediatrician and the other a Research Pharmacist, both in hospitals in England. I am also very proud of my two young grandchildren whom I hope to spend a lot more time with when I finally do retire. They live in Oxfordshire which is three and half hours away from me.

I am just past retirement age but wish to keep working as long as I can positively contribute. I feel if I do retire, PPS might catch up with me and I will then become a burden. This is not my way or as I know the way of many other people who once had Polio.

Frances Duncan

Tell it your way – My Way book to be launched

The ever popular My Way articles that feature so prominently on the back page of **the bulletin** are going to be pulled together to produce a book. This is in part to celebrate the 80th Anniversary, but also in recognition of the stories from all the Fellowship's wonderful members. **the bulletin** Editorial Team is now beginning to collate more My Way stories to include 80 for the Anniversary. Included will be stories that have already been printed as well as new ones, so please do send them on to thebulletin@beyondpr.co.uk. The books will be on sale via The British Polio Fellowship website in due course.



**British Polio
Fellowship
1939-2019**

Please send your My Way submissions and photographs to thebulletin@beyondpr.co.uk

As space is limited, regrettably we can usually only publish a maximum of 600 words and only one or two images